

Improving Health Care with Drug Users

Tools for Non-Clinical Providers

Participant Workbook



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Developed by the Harm Reduction Coalition
with funds from the New York State Department of Health AIDS Institute

COURSE AT-A-GLANCE – 3 HOURS

Module 1: Anonymous Survey and Introductions

Anonymous Survey Exercise
Participant and Trainer introductions
Goals, Objectives and Guidelines

Module 2: Harm Reduction and Framing the Issue

Harm Reduction Principles Review
Discussion: Framing the Issue

Module 3: Health Care Values and Drug Users

Activity: Health Care Values
Discussion: Patient-EASE
Discussion: Drug User Access to Care

Break (10 minutes)

Module 4: “Quality Health Care is Your Right” Workshop Curriculum and Booklet

Introduction to the Curriculum and Booklet
Activity: Health Care Perspectives
Discussion: Tips for Facilitators

Module 5: Strategies Review

Discussion: Strategies for Improving Health Care with Drug Users

Module 6: Closing and Evaluations

Improving Health Care with Drug Users

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*Harm Reduction Coalition
2010*

2.

Goals

- ⦿ Explore factors that influence drug users' access to and experience with health care.
- ⦿ Identify tools and resources to encourage better encounters between drug users and the health care system.
- ⦿ Develop skills for working with drug users on health care issues.

Introductions

- ④ Name
- ④ Organization (if applicable)
- ④ One word that comes to mind when you think of health care with drug users

Training Guidelines

- Step up, Step Back
- Non-Judgment
- Talk *with* each other, not *at* each other
- Agree to disagree
- Confidentiality

Harm Reduction

- Pragmatic → Acknowledges reality
- Non-judgmental, non-punitive, non-coercive
- Not hinged on abstinence
- Low-threshold
- User driven

Why drug user health care?

- Drug use is associated with several unique health risks
- Drug users with the most needs are less likely to access health care on a regular basis
- Stigma and mistrust play a large role

Focus on HIV and Viral Hepatitis

- ◎ HIV and viral hepatitis prevention, care and treatment must be placed within the broad context of health care.
- ◎ Injection drug use accounts for ~16 percent of new HIV infections in the US.
- ◎ Hepatitis C Virus (HCV) among IDUs remains high.

Common misconceptions

Drug users don't care about their health

- *Proven false by syringe access /decreases in HIV, HCV*

Drug users can't manage medication regimens

- *Proven false by HIV and HCV treatment experience*

Drug users are only interested in getting narcotics

- *There are actually much easier ways to get drugs*

What is "Quality" Health Care?

What are specific qualities that YOU value in your own health care?

What are specific qualities that you value in health care
REFERRALS for clients?

Patient-EASE

- **Patient**-centered
- **Efficient** and Coordinated
- **Accessible**
- **Safe** and Confidential
- **Effective/Competent**

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Where Do Drug Users Access Health Care?

- Emergency Rooms
- Clinics/Health Centers
- Syringe Exchange Programs (SEPs)
- Methadone/drug treatment programs
- Self-medicate

Barriers to Quality Care

Structural/ Institutional

- Ex:
High Threshold Services

Individual/ Personal

- Ex.
Stability

Social/ Community

- Ex.
- Power Dynamics/Stigma

Break!

- 10 minute break -

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“Quality Health Care is Your Right”: Workshop Curriculum

- 90-min workshop w/ drug using clients
- Promotes discussion about relationships with health care providers
- Reflects on meeting both drug users & health care providers “where they are at”
- Concepts can be incorporated into everyday dialogue.

Companion Booklet

Why Go

When to Go

Where to Go

Paying for Health Care

How to Prepare

What to Expect

Talking About Drug Use

Tips for Communicating

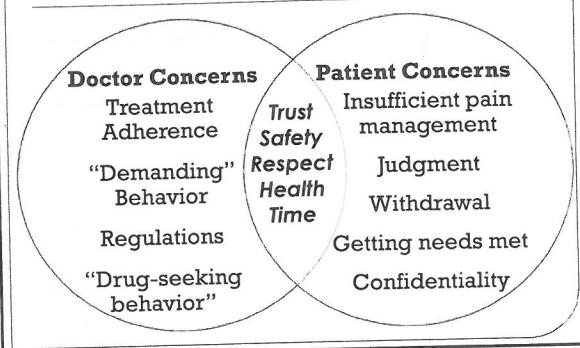
Before You Leave and After the Visit

Small Group Exercise

GOAL: Practice the small group exercise and explore health care needs from the perspective of both HC providers and drug users.

- ◎ Perspectives:
 - Health Care Provider
 - Drug user
- ◎ Strategy Session and Reflection

Doctor-Patient Relationships



Tips for Facilitators

- ◎ Plan well, know what you hope to get from the session
- ◎ Take advantage of "teachable moments"
- ◎ Use probing techniques
- ◎ Allow for silence/reflection

Strategies Review

- ◎ Keep the dialogue open
- ◎ Help participants navigate systems
 - Make it work for them!
- ◎ Create *information rich* referral guides
- ◎ Use a holistic approach
 - Ex: Housing is health care!

Summary

Cultural Competency

Patient-EASE

It's all about the relationship!

Anonymous Survey

Consider the following statement. Either in your head or on paper mark the box that most accurately reflects your response to the statements below.

Please do not put your name on this paper.

There are no right or wrong answers and these papers will not be collected.

| Statement | Strongly Agree | Agree | Disagree | Strongly Disagree |
|--|----------------|-------|----------|-------------------|
| Most drug users don't consider their health care to be a priority. | | | | |
| People should always talk to their doctors about their drug use. | | | | |
| Sometimes I feel sorry for the people who use our services. | | | | |
| If someone has a history of drug use, they probably should not be given addictive pain medication. | | | | |
| There are safe ways to use, and even inject, street drugs. | | | | |
| Drug users can manage taking complicated medication regimens as prescribed. | | | | |
| Most drug users will probably be late to their doctor visits, if they make it there at all. | | | | |
| Most drug users don't know how to deal with pain because they are so used to taking drugs as a coping mechanism. | | | | |
| Doctors have a good understanding of how to work with drug users. | | | | |
| Drug users are probably more difficult health care patients than non-drug users. | | | | |

Adapted from *Using Harm Reduction to Address Sexual Risk with Drug Users and Their Partners*, HIV Education and Training Programs, NYSDOH AIDS Institute, by Joanna Berton Martinez, August 2009.

Some of the statements on this exercise were borrowed from Project Implicit and their Implicit Association Tests, <https://implicit.harvard.edu/implicit/>

IMPROVING HEALTH CARE WITH DRUG USERS

STRATEGIES FOR PROVIDERS

| STRATEGY | EXPLANATION |
|--|--|
| Maintain a position of non-judgment | <p>Like drug use, health care and self-care in general can be a sensitive issue for people to talk about. The safer people feel in disclosing any behaviors, even those that may be risky or compromising to their health, the more likely they will be to keep the lines of communication open.</p> <p>It can be difficult to watch people make choices that are unhealthy or harmful. It is important to have outlets to explore one's own judgments and feelings so as to avoid burdening the client these issues.</p> |
| Communicate honestly | <p>Clients will often respect when people are honest and direct, even about issues that may be difficult. It is okay to ask questions, express concerns and confront contradictory behavior.</p> |
| Help clients prepare for their medical appointments | <p>Offer to make calls to schedule appointments with and/or for clients.</p> <p>Help clients call providers and plan realistic appointment times. Also, ask clients if they would like you to remind them of their appointments a day or two ahead.</p> <p>Talk to clients about what to expect from health care visits (ex. long waits, the kinds of questions to expect, etc). Also, help clients collect any necessary documents or identification that they will need to bring to the appointment with them.</p> <p>Help clients research/understand health conditions and medication side effects; help them maintain an up-to-date list of their medications and doctors.</p> <p>For clients who do not have health insurance and are eligible for Medicaid or other public insurance it can be helpful to help guide them through the process. Also, advising people to enroll for any health insurance plans early is very important.</p> <p>For clients who may need to provide a mailing address, see if your agency can collect mail.</p> |

| | |
|--|---|
| Create information-rich referral guides | <p>Create referral guides that include known harm reduction providers and feedback from other clients.</p> <p>When creating referral guides, it can be helpful to:</p> <ol style="list-style-type: none"> 1) Set up a grading or rating system to indicate quality of care, knowledge of harm reduction/experience working with drug users, and other components of care. 2) Include “reviews” from clients who access services with different providers/health care center. |
| Escort participants to visits to provide support and advocacy. | <p>It may be easier for clients to seek health care if they have someone to go with them.</p> <p>Health care providers may respond differently to people when they know that there are other people looking out for and caring for them.</p> |
| Help clients with record-keeping. | <p>It can be useful for providers to keep copies of birth certificates, IDs and medical records for clients – especially in cases where people may be in between housing, homeless and/or transient.</p> |
| Assist clients in establishing stable housing. | <p>Unstable housing not only has its own impacts on the physical and mental health of individuals, it can also be a significant barrier for accessing and maintaining relationships with health care and doctors. Identifying housing resources or programs, and assisting those clients who are interested in obtaining more stable or permanent housing with the process of securing housing can sometimes be an important and necessary step toward addressing other health needs.</p> |
| Work with clients around mental health issues. | <p>Similar to housing, mental health issues can pose significant barriers to self-care and maintaining overall health. Providers can help clients address mental health issues in many ways, including:</p> <ul style="list-style-type: none"> - Helping to connect clients with nonjudgmental psychiatrists - Helping clients to manage their medication schedule - Working with clients to avoid disruptions in medication due to lapses in insurance or other issues, etc. - Counseling in an open and nonjudgmental way that will keep the lines of communication open. - Working with clients to explore their options. |
| Create safe spaces for clients to talk about drugs (the positive and the negative aspects of drug use). | <p>It is not often that drug users get to explore all of the aspects of their drug use. Given that drug use often comes with any number of negative consequences (and that these are usually the factors that people ask about and highlight) it is important to acknowledge the reason that people DO use drugs as well. By doing this, it may also be possible to find alternative ways to meet the same needs (if the drug user wants to). Trust is also built when there is allowance for drugs and drug use to be multidimensional.</p> |

Quality Health Care is Your Right!

A Workshop for Drug Users about Health Care

Curriculum Guide for Workshop Facilitators

**Developed by the Harm Reduction Coalition
for the New York State Department of Health AIDS Institute**

Acknowledgments

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About the Harm Reduction Coalition:

The Harm Reduction Coalition is a national advocacy and capacity-building organization that promotes the health and dignity of individuals and communities impacted by drug use. HRC advances policies and programs that help people address the adverse effects of drug use including overdose, HIV, hepatitis C, addiction, and incarceration. We recognize that the structures of social inequality impact the lives and options of affected communities differently, and work to uphold every individual's right to health and well-being, as well as in their competence to protect themselves, their loved ones, and their communities.

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Activity: Health Care Perspectives

Alternate Exercise: Talking About Drug Use Role Play

Module Three: Quality Health Care is Your Right: The Booklet (10-15 min)

Module Four: Conclusion and Evaluations (5-10 min)

Workshop Participant Training Materials:

Drug User Perspective Scenario/Strategy Session Worksheet

Health Care Provider Scenario/Strategy Session Worksheet

Role Play Scenario Worksheet

Quality Health Care is Your Right Booklet

Workshop Evaluation

INTRODUCTION

Quality Health Care is Your Right is a workshop curriculum designed (1) to engage drug users around health care issues and (2) to develop strategies for improving relationships between drug users and health care providers.

The workshop is meant to begin a conversation about health care with drug users. The discussions and strategies discussed in the workshop can serve as a platform for highlighting issues that may require additional focus or priority areas for individual work with clients. The workshop also allows participants a valuable opportunity to share valuable experiences and resources with each other that lead to an ongoing exchange of information.

Quality Health Care is Your Right was developed from the understanding that active drug users – individuals likely to have an excess of health care needs – are also among the least likely to receive quality health care. This situation is often further exaggerated by issues related to race/ethnicity, sexual orientation and gender, economic and housing status, HIV and Hepatitis C status, among others. Unfortunately, the predominant experience between drug users and health care providers is one devoid of trust on either side of the relationship. This often leads many drug users to avoid health care altogether and many doctors to spend very little time trying to understand the actual health needs of their drug using patients. The dynamic between many drug users and the health care system is often built more around mutual judgment, stereotypes and manipulation than the communication, engagement, and teamwork that should be expected from health care relationships.

Drug users may find it difficult to access health care and may not even seek care for any number of reasons, including fear that they may be mistreated or judged, that they have had previous negative experiences with health care, or that they may not know what to expect or where to go. In addition, health care providers may act with prejudice or discrimination built on a belief that people using drugs do not care about their own health and can't take care of themselves as long as they are currently using. When health care providers focus more on drug use and ignore the true needs or concerns of the individual, the patient is likely to become guarded and defensive, perhaps even hiding certain information, in an effort to have their concerns addressed. Despite the existence of a Patient's Bill of Rights and outlets to report inappropriate physician behavior, the pervasive stigma around drug use may leave patients feeling disempowered. This can lead to a cyclical pattern of self-fulfilling prophecies and unjust discriminations, which ultimately harm the health of drug users while taxing the entire medical infrastructure.

In an effort to help drug users develop strategies and tips for navigating the health care system and help them get the most out of their medical care, we have developed the booklet, "Quality Health Care is Your Right: A Guide for Drug Users to Health Care." This curriculum was created to promote discussion around the ideas and tactics outlined in the materials and to tap into the expertise of drug users themselves as a means of sharing insight, planning, and problem-solving toward the goal of getting what they need and want from health care.

CURRICULUM GOALS AND OBJECTIVES

Curriculum Goal

The goals of this curriculum are to:

- 1) Generate discussions about health care among drug users.
- 2) Improve relationships between drug users and health care providers.
- 3) Make it easier for drug users to get what they want out of health care.

Curriculum Objectives

Upon completion of this workshop, participants will be able to:

- Identify barriers to health care for active drug users through an exercise and group discussions exploring common drug user experiences and needs.
- Anticipate common concerns health care providers have about working with active drug users by facilitating an exercise and discussion that explores what providers need to do their jobs, as well as the myths and misconceptions they have about active drug users who seek health care.
- Evaluate positive and negative factors that may influence relationships with health care providers through a group activity exploring provider and patient perspectives.
- Identify strategies for drug users to employ with health care and health care providers through a group activity exploring trust between patients and doctors, and through conversation about the booklet, *Quality Health Care is Your Right*.
- Describe strategies for talking about drug use in health care settings with an activity that considers the needs of both a drug user and a doctor, as well as with discussion of strategies outlined in the companion booklet, *Quality Health Care is Your Right*.
- Explain reasons why it is important for active drug users to take a proactive role in their own health care by engaging in facilitated discussion and activity about misconceptions among providers and patients, as well as how to develop positive health care relationships.

Curriculum Audience

People who use drugs or have a history of drug use who are interested in building healthier relationships with health care and health care providers.

Suggested Number of Participants:

Ideal group size is 6-10 participants.

It is recommended that workshop size be limited to no more than 12 participants.

In cases where groups are larger, we recommend:

- Utilizing 2 facilitators.
- Extend the workshop to at least 2 hours, or more.

HOW TO USE THIS CURRICULUM

A companion to the booklet *Quality Health Care is Your Right*, this curriculum is intended to help drug users focus and capitalize on their own knowledge and experience toward building stronger relationships with doctors and health care. The curriculum centers on participant input, while relying on the facilitator to move discussion forward, create cohesion and highlight common themes. Group activities drive the curriculum in an effort to promote ownership over ideas and suggestions, some of which may also be included in the companion booklet.

This workshop is presented as a one and one-half hours interactive workshop to be facilitated in four modules. Each module in this curriculum is presented includes the following:

- An **introduction** including goals and objectives of the module.
- **Time** needed to complete the module
- **Preparation** and **materials** necessary for the module
- An **explanation** of module activities
- **Facilitation procedures** for module activities
- **Key points** that are important to cover and highlight during the module

Module one includes a welcome and introduction, outlining why the workshop was developed and what participants can expect from the session. It also includes an activity for participants and facilitators to briefly get to know one another.

Module two uses an interactive activity to promote conversation and brainstorming about health care. It encourages participants to explore ideas from the perspective of both health care providers and patients. The activity uses drug users' own knowledge and experience to generate strategies for developing trust with health care providers.

Module three introduces participants to the booklet *Quality Health Care is Your Right: A Guide for Drug Users to Getting Better Health Care*, and provides an opportunity to draw connections to conversations and issues raised in Module Two and closes the workshop.

Module four wraps up the session and gives participants an opportunity to highlight important ideas.

The workshop is not scripted although suggestions are offered with regards to key points, communicating important information and general facilitation techniques. Facilitators are encouraged to be creative in the presentation of material, adjusting to the needs of each group as well as the relationship between members of the group and the facilitator. For example, if the group meets on a regular basis, people know each other and there is already an established rapport, the discussion may be different than in a group where people don't yet know each other.

The workshop is intended to be delivered from a harm reduction perspective with active drug users. Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use to managed use to abstinence. Harm reduction strategies meet drug users "where they're at," addressing conditions of use along with the use itself.

While this workshop does encourage participants to consider any factors that impact their experience with health care, it does not assume that participants want or need to make changes to their drug use.

The curriculum relies on the facilitator to create an environment that will promote participation, feedback and excitement from participants. The facilitator should be comfortable working with active drug users and familiar with the issues discussed in the workshop. It is important that the facilitator have the skills necessary to generate discussion and move conversations forward in small-to-larger group settings, even around issues that may be sensitive. It will also be necessary for the facilitator to balance different perspectives and articulate main points in order to make the entire session useful for all participants. Facilitators should be mindful of language and comprehension throughout the session, avoiding complicated medical jargon or other terminology that may be difficult for everyone to understand.

In addition to the format presented here, we encourage using the ideas and strategies outlined in this curriculum to facilitate discussion during counseling or case management sessions, with support groups at syringe access programs or in any number of other settings.

Creating a Welcoming Space

Learning takes place best in environments where people feel *safe and relaxed*. This workshop relies on active participation from workshop attendees; therefore it is important to create a comfortable space in which participants feel open to the process of learning and sharing.

Food is good for the mind and the body! If possible, provide snacks and/or coffee or soda, not only as a comfort, but also to provide energy and engagement. Participants also feel valued when they receive these kinds of offerings.

When deciding where to hold the workshop, choose a *space that is comfortable* – be mindful of issues such as accessibility, natural light, room size, room set-up (including table/chair arrangement), comfort of the chairs, temperature of the room, and other related issues. Hold the workshop in a place where drug users will feel safe such as a syringe access program, community-based organization, AIDS service organization, drop-in space or other place where drug users know that their confidentiality will be respected and their experiences valued without judgment. Drug users are less likely to feel safe in a sterile or medical environment, or one that is too formal.

Welcome individual participants as they arrive, introducing yourself. Also, it's recommended that the facilitator dress and engage in a way that is professional, yet informal enough that participants can feel at ease.

MODULE ONE: INTRODUCTIONS AND WHAT TO EXPECT

Goals

The goals of this module are to:

- ▶ Introduce participants to workshop goals and provide background on why the workshop was developed.
- ▶ Introduce workshop participants to one another.
- ▶ Encourage active participation and to develop trust and a sense of commonality among the group.

Objectives

After completing this module, participants will be able to:

- ▶ Identify why the workshop was developed through discussion about the training development.
- ▶ Understand the benefits of active participation in and completion of the workshop by learning about activities planned for the workshop.
- ▶ Describe participant expectations for the workshop by listening to and participating in a round of introductions.

Time

30 minutes total, depending upon the number of participants

| | |
|----------------------------------|------------|
| Activity A: Welcome and Overview | 5 minutes |
| Activity B: Introductions | 20 minutes |

Materials

- ▶ Clock
- ▶ Newsprint/flip chart/large paper
- ▶ Markers
- ▶ Tape for newsprint
- ▶ *Optional: Name tags helpful if the group does not know each other already*

Module 1 - Activity A: Welcome and Overview

Explanation

This activity will welcome participants to the workshop, provide a context for the workshop and explain what can be expected from the session.

Preparation

If the room allows, arrange participant chairs in a circle. Otherwise, arrange the room in a way that is as conducive to group conversation as possible. For the group activity portion of the workshop, participants will be divided into groups. Ideally, each group will be at its own table. If tables are available, consider seating people around two tables that can easily be separated for the activity.

Prepare and hang newsprint with the name of the workshop and the name of the facilitator:

Quality Health Care is Your Right!

A Workshop for Drug Users about Accessing Health Care

Facilitator Name: _____

Procedure

- 1) Once the majority of your expected participants have arrived, welcome the group.
- 2) Introduce yourself, offering some information about your experience and expertise.
- 3) Provide an overview of the workshop that explains why the workshop is being held, what participants can expect from the session and workshop goals:
 - ▶ To help drug users get more involved in their own health care.
 - ▶ To make it easier for drug users to get what they want out of health care.
 - ▶ To come up with strategies for improving relationships to health care and health care providers.
 - ▶ To introduce the booklet, *Quality Health Care is Your Right!*

Key Points

- *Thank the participants for taking the time to come to the workshop.*
- Outline the timeline for the training. Explain that because the training is only one and one-half hours, there is not a planned break, and that at times you may need to move discussion forward to get people out of the workshop on time.
- When describing why the workshop was created, it is important to acknowledge difficulties that many drug users face getting good care, acknowledge that people may have experienced a great deal of prejudice or discrimination in the past, and emphasize that it is possible to get good care, and that it is in fact their right.
- Emphasize the value of participant feedback during the session:
 - Each individual is the expert on their own needs
 - The success of the workshop depends on the knowledge that participants bring with them.

Module 1 - Activity B: Introductions and Guidelines

Explanation

This activity will help participants and facilitators get to know each other, build a sense of commonality and group cohesion and create an environment that will promote active participation.

Preparation

Prepare 2 piece of newsprint:

Introductions

What is your name?

What brings you here?

Guidelines

- ★ *Be respectful of others.*
- ★ *Discuss instead of argue – agree to disagree when necessary.*
- ★ *There are not right or wrong answers – just ideas to explore. If you have an idea, put it out there.*
- ★ *Be an active participant – the workshop relies on your expertise.*

Procedure

- 1) Explain to the participants that they are being asked to participate in an activity that will help the group get to know each other better.
- 2) Next, ask each participant to introduce themselves by:
 - ▶ Saying their name – so that we can speak with each other by name;
 - ▶ Explaining briefly what brought them to the workshop - even if they were simply told to be there or wanted to receive compensation/travel for attendance – in an effort to meet participants' expectations and goals throughout the workshop;
- 3) Once everyone has introduced themselves, highlight common expectations or interests in the room and/or speak to the importance and value of different perspectives.
- 4) Before concluding the introductions, explain that you would like to know a little more about experiences that people have had with health care in the past.
 - ▶ Ask the group to think about experiences that they have had with health care that made an impression on them – either positive or negative.
 - ▶ Next, ask if there is ONE person willing to share 1 **negative experience**, and ANOTHER person willing to share 1 **positive experience**. Only 2 people will present experiences – *not the entire group*. It is necessary to limit sharing in this section to allow sufficient time for the other activities.
 - ▶ When people share, ask if others have had similar experiences.
 - ▶ Use the negative example as an **opportunity** to begin exploring **strategies** for turning around negative experiences, possibly pointing to information in the *Quality Health Care* booklet.

- 5) **Ask the group if they can agree upon some general guidelines for the rest of the session.** Given the time restrictions it will be necessary to propose a set of guidelines for the group to agree upon.
 - ★ *Be respectful of others.*
 - ★ *Discuss instead of argue – agree to disagree when necessary.*
 - ★ *There are not right or wrong answers – just ideas to explore. If you have an idea, put it out there.*
 - ★ *Be an active participant – the workshop relies on your expertise.*
- 6) Thank the group for their participation during the introductions.

Key Points

- Model the activity by introducing yourself and answering the prompt questions first.
- It may be helpful to write notes of participant responses on additional pieces of newsprint. If possible, keep the sheets posted throughout the workshop for reference.
- Ensure that everyone has a chance to introduce themselves, even those who may come in late.
- Give participants an opportunity to offer additional Guidelines for the session.

MODULE TWO: MAKING HEALTH CARE WORK

Goals

The goals of this module are to:

- ▶ Explore drug user attitudes about health care and health care providers.
- ▶ Develop and hone drug user strategies for navigating the health care system.
- ▶ Explore the expertise and knowledge that participants bring to the workshop.

Objectives

Upon completing this module, participants will be able to:

- ▶ Identify qualities in health care relationships that may be important to drug users by completing an activity and discussing qualities that are meaningful to them.
- ▶ Identify needs of health care providers by participating in an activity that encourages them to explore health care from a provider perspective.
- ▶ Name strategies for building trust with health care providers by using group feedback and ideas from other participants during group activity and discussion.
- ▶ Explain concerns that drug users may have in relation to seeking health care by exploring a health care scenario and having a facilitated discussion with other participants.
- ▶ Explain concerns that health care providers may have in relation to drug use among their patients by exploring a health care scenario and having a facilitated discussion with other participants.
- ▶ Clarify strategies for talking about drug use in a health care setting through group activity and facilitated discussion that explores common concerns for disclosing use as well as medical reasons why disclosure can be valuable.
- ▶ Specify qualities within health care that make it easier for drug users to seek and access services through a group activity that encourages participants to think about preparing for health care and building trust.

Time

40 minutes total

Materials

- ▶ Clock
- ▶ Newsprint/flip chart/large paper
- ▶ Markers
- ▶ Tape for newsprint
- ▶ Drug User Perspective Scenario/Strategy Session Worksheet
- ▶ Health Care Provider Scenario/Strategy Session Worksheet

} Alternately:
} Role Play Scenario Worksheet

- ▶ Prepared Newsprints for the Perspectives Exercise, examples below:

Patient Perspective Group:

| Thinking as Regina: | |
|---|---|
| It might be important for me to talk about my drug use because: | I might not want to talk about my drug use because: |
| | |
| Things that make me trust my doctor MORE: | Things that make me trust my doctor LESS: |
| | |

Doctor Perspective Group:

| Thinking as Dr. Davidson: | |
|--|---|
| It matters if my patient talks about her drug use because: | It doesn't matter if my patient talks about her drug use because: |
| | |
| Things that make me trust my patient MORE: | Things that make me trust my patient LESS: |
| | |

Group Brainstorming Strategy Session:

Building Strategies:

1 strategy to build trust between doctors and patients:

1 strategy to talk about drug use with doctors (or how to *not* talk about it):

1 thing that patients can do to prepare for successful health care visits:

Module 2 - Activity A: Perspectives on Health Care Exercise

Explanation

This small group exercise is developed to offer drug users an opportunity to consider their own health care needs, as well as the needs of the provider, in an effort to find common ground and promote healthier relationships.

This exercise will be used to:

- ▶ Think creatively about the relationships between drug users and doctors and/or the health care system.
- ▶ Help participants identify strategies to better meet their health care needs.

The exercise offers participants an opportunity to have casual, structured conversations about health care scenarios, using key questions to guide the discussions. Workshop participants are divided into groups and asked to evaluate a scenario from an assigned perspective – in this case, either drug users seeking health care or health care providers.

In the first round of the exercise, each group is given 2 key questions to guide their conversations and probe key areas of discussion (each question has 2 parts). Participants in the *Patient* group are encouraged to explore needs of drug users when preparing for health care, concerns related to drug use disclosure, and how to build trust with doctors. Participants in the *Provider* group are asked to explore why doctors may need certain information from patients, the role of drug use on health and health care needs, and aspects of building trust between doctors and patients.

After each group has had a chance to discuss their scenario and questions, the groups will report back to the larger group about the main ideas that came up in the conversations. Using points from both perspectives, the larger group will then collectively brainstorm strategies for improving health care relationships.

This model creates an engaging and interactive environment wherein participants can learn from each other and build upon their existing knowledge. The exercise is built on the foundation that drug users are the experts in their own lives and that workshop participants already have the expertise and insight necessary to address health care issues, though they may need support in teasing out and identifying strategies. In addition, by looking at the scenarios from different perspectives, participants are encouraged to take health care provider needs into consideration in a new way, which may in turn foster stronger relationships between providers and drug users. The facilitator is available to move the activity forward, stimulate conversation, clarify questions and highlight strategies.

Preparation

- ▶ Prepare the Scenario Worksheets for groups to use as a guide during the activity. Worksheets can be found at the end of the Curriculum. *Make enough copies so that each participant has a copy of the scenario.*

- ▶ Prepare 3 pieces of newsprint pages. Sheets 1 and 2 will be distributed to the groups with markers and Sheet 3 will be used during the collective brainstorming strategy:

Label 3 pieces of newsprint as follows:

Sheet 1 - Group A: Thinking as Regina

This sheet will be given to the Patient group to record their thoughts.

| Thinking as Regina: | |
|---|---|
| It might be important for me to talk about my drug use because: | I might not want to talk about my drug use because: |
| | |
| Things that make me trust my doctor MORE: | Things that make me trust my doctor LESS: |
| | |

Sheet 2 - Group B: Thinking as Dr. Davidson

This sheet will be given to the Provider group to record their thoughts.

| Thinking as Dr. Davidson: | |
|--|---|
| It matters if my patient talks about her drug use because: | It doesn't matter if my patient talks about her drug use because: |
| | |
| Things that make me trust my patient MORE: | Things that make me trust my patient LESS: |
| | |

Sheet 3 – Strategy Brainstorm:

This sheet will be used during the Group Brainstorming Session to record feedback and strategies. Use more paper if necessary.

Building Strategies:

1 strategy to build trust between doctors and patients:

1 strategy to talk about drug use with doctors (or how to *not* talk about it):

1 thing that patients can do to prepare for successful health care visits:

Procedure

- 1) Separate participants into 2 groups. If the group is larger, divide participants into an *even number* of smaller groups.
- 2) Briefly introduce the exercise:
 - ▶ *Why are you doing the exercise?*
Present Goals:
 - To explore the relationship between drug users and doctors and/or the health care system from different perspectives
 - To help you come up with strategies for getting what you from health care
 - ▶ *What can participants expect from the exercise?*
 - Explain that each small group will have a conversation and then we will come back together as a group to discuss what they talked about and build some strategies together.
 - Everyone will be encouraged to participate.
 - Each group will be asked to summarize important ideas from their conversations. The groups can choose a representative, or report-back together.
 - ▶ *How long will the exercise take?*
About 40 minutes

3) Exercise Instructions:

- ▶ *Assign each group a perspective:* Health care providers or Drug users seeking health care (If there are more than two groups, assign each perspective to more than one group.)

Explain to each group that they are being asked to “think from the perspective” that they have been assigned, but use information from their own experiences to come up with ideas.

- ▶ *Distribute prepared worksheets and blank newsprint to each of the groups.* Quickly summarize the scenarios and questions.

→ **NOTE:** For the “Dr. Davidson” group, it is important to emphasize that **you do not expect participants to become medical experts or make diagnoses** – the focus is to think about basic expectations and goals a doctor may have.

- ▶ *Give groups markers and explain that one or more people from each group should write down important points that come up.*
- ▶ *Perspectives Discussion:* Give the groups 10-15 minutes to discuss their scenario. During this time, it is important for the facilitator to move between the groups, clarifying any questions and offering direction as needed. Remind people to write down all of their ideas. A few minutes before the round is over, ask the groups to start wrapping up the discussion.

→ **NOTE:** The “Dr. Davidson” group may need more initial support since the natural inclination for participants will likely be to think as the patient. Remind the “Dr. Davidson” group that they are being asked to think from the Dr’s perspective.

- ▶ When the groups have completed their individual discussions, **ask each group about 5 minutes** to summarize the main points of their discussions.

- ▶ *Strategy Brainstorming Session:*

Next, bring the entire group back together. Explain that you want the group to use information from the “2 sides” to come up with a couple of strategies to improve health care relationships.

With the entire group, review the Strategy Brainstorming Questions on the third sheet of prepared newsprint. Facilitate a group discussion using the main points from the small group discussions to highlight and explore strategies for improving relationships with health care.

Facilitators can use this section as an opportunity to highlight:

- *The role of factors such as race, culture, class, infection status, etc. on the scenario*
- *Additional factors that could impact the scenario, such as if the patient has kids, age, language barriers, etc.*
- *Structural/Institutional barriers to health care*
- *Special issues relevant to the group you are working with (HIV, HCV, methadone, specific drugs that people use, immigrants, mothers/parents, etc.)*

- ▶ Thank the group for participating in the activity.

Key Points

- ***Emphasize to participants that there are no right or wrong answers in these conversations. Encourage people to say whatever is on their mind!***
- It can be helpful to have some examples ready to offer the groups in case they get stuck. Alternately, the facilitator can present a couple of examples as you introduce the exercise.
- During break-out groups, the facilitator should float between groups to help move discussion forward, answer questions and offer direction as needed.
- During discussion, facilitators can identify themes and common experiences, tease out additional strategies and identify areas for special focus or additional thought.
- Be mindful of time. Give groups a heads-up a couple of minutes before the end of discussion rounds – encouraging people to wrap up last thoughts.
- ***Thank everyone for their participation upon completing the activity.***

Module 2 - ALTERNATE Exercise: Role Plays (40 minutes)

This exercise is offered as an alternative or follow-up to the small group exercise described above.

It may also be used one-on-one with individual clients.

This exercise is not meant to be delivered in the same session as the small group exercise, but rather as an alternative or follow-up exercise.

It may work best:

- In groups where participants know each other already.
- As a separate follow-up session, giving participants a chance to practice strategies developed in the small group exercise.
- One-on-one with individual clients.

Explanation

Participants will be asked to role play an interaction between a health care provider and a drug user seeking health care. The activity will give participants an opportunity to explore strategies for communicating important health care issues and needs, as well as to consider the needs of health care providers.

Preparation

Make copies of the role play worksheets for distribution to participants.

Procedure

1) Introduce the exercise.

Explain that participants will work in pairs to “real play” or role play a scenario between a drug user and a health care provider.

Ask if everyone knows what a role play is and explain what it is if there is anyone who seems unsure.

There will be **two rounds** so that each person can have a chance to be both the health care provider and the drug user.

Also present the goals of the exercise:

- To explore the relationships between drug users and doctors and/or the health care system from different perspectives
- To help participants come up with strategies for getting what they need from health care

2) Ask the participants to pair up.

NOTE: If there are an odd number of participants, one group will have 3 people. The third person can:

- Role play as an advocate, someone going to the doctor with the patient to help advocate on their behalf
- Participate as an observer, who will be an actor in the second round, but act as an observer to give feedback after the role play.
- Role play with a facilitator, in cases where there are 2 facilitators.

- 3) Ask each pair to decide who will be the drug user and who will be the health care provider for the first role play.
- 4) Distribute role play worksheets to each of the pairs. Briefly review the scenario, and the special points for each character ("Regina" and "Dr. Davidson").
- 5) Ask the group if they have any questions before beginning the role play. If there is confusion, consider asking someone to volunteer to model the activity with you.
- 6) Begin the first round of role plays.
- 7) After groups have been role playing for about 5-7 minutes, ask participants to stop for a brief discussion.

Ask participants questions to generate discussion:

- How did it feel to be the drug user?
- How did it feel to be the doctor?
- What were some strategies people used to talk about drug use?
- What were some strategies people used to encourage trust in the relationship?

- 8) **NEXT:** After a 5-7 minute discussion, ask people who were just health providers to raise their hands. Then, ask people who were just patients to find *a new partner* from the health care provider group. Explain that for the next role play, the perspectives will shift – the patients become the doctors and the doctors become the patients.
- 9) Prompt people to begin the second role play with their new perspectives.
- 10) **NEXT:** After about 5-7 minutes, ask participants to stop for a discussion.

Ask participants questions to generate discussion:

- How did it feel to take on the other perspective?
- Were people able to use any of the strategies talked about in the first round?
- What were some new strategies people used to talk about drug use this round?
- What were some new strategies people used to encourage trust in the relationship?

- 11) Conclude by asking people what they thought of the exercise:
 - What were some important things that people learned from doing the role plays?
 - What worked well? What didn't work as well?

Key Points

- If participants seem unsure about how to do a role play, it may be helpful to model the role play in front of the group first – asking for a volunteer to help you.
- During role plays, the facilitator should float between groups to observe, identify strategies that are being used and get ideas for additional discussion.
- During discussion, facilitators can identify themes and common experiences, tease out additional strategies and identify areas for special focus or additional thought.
- Be mindful of time. Give groups a heads-up a couple of minutes before the end of each role play – encouraging people to wrap up.
- ***Thank everyone for their participation upon completing the activity***

MODULE THREE: QUALITY HEALTH CARE IS YOUR RIGHT: THE BOOKLET

Goals

The goals of this module are to:

- ▶ Introduce the booklet *Quality Health Care is Your Right: A Guide for Drug Users to Getting Better Health Care* as a tool for participants to use when navigating health care.
- ▶ Encourage ongoing thought and discussion among drug users about issues related to health care.

Objectives

After completing this module, participants will be able to:

- ▶ Identify common areas of concern between drug users and the health care system by highlighting sections of the companion booklet and discussing main points.
- ▶ Describe issues related to health care that are important to them through a facilitated discussion about the workshop activities and materials.

Time

10-15 minutes total

Materials

- ▶ Clock
- ▶ The booklet: *Quality Health Care is Your Right!: A Guide for Drug Users to Getting Better Health Care*
- ▶ *Additional handouts (Optional):*
 - List of Local SAP providers
 - List of OASAS providers that will serve pregnant women
 - Any additional local health care services that may be useful.

Module 3 - Activity A: Quality Health Care is Your Right

Explanation

This activity is meant to introduce the booklet *Quality Health Care is Your Right: A Guide for Drug Users to Getting Better Health Care* to workshop participants and to emphasize strategies and issues identified during the previous exercise.

Preparation

Obtain copies of the booklet *Quality Health Care is Your Right: A Guide for Drug Users to Getting Better Health Care*.

Procedure

- 1) Distribute copies of the booklet to participants. ***Acknowledge that the booklet relies on being able to read. Explain that if people need help, they can ask their provider to go over it with them.***
- 2) Review the main sections of the booklet with participants, highlighting the different topic areas that are covered.
- 3) Highlight strategies from the booklet that were also discussed in the previous exercise.
- 4) If there is time, highlight and discuss additional strategies that are listed but were not brought up in the previous exercise.
- 5) If there is time, ask participants to point out sections of the booklet that seem to be the most relevant to them. Encourage additional discussion about how to make the strategies work best for participants.
- 6) Distribute any additional handouts.

Key Points

- Given time restrictions during the session, there may not be much time to go through the booklet in detail. If time has run out, still distribute the booklet for participant to reference at their leisure.
- ***Being very familiar with the booklet will make it easier to weave the strategies and messages that it covers throughout the entire session. This will make it easier to highlight areas in the booklet quickly during this module.***

MODULE FOUR: CONCLUSION AND EVALUATIONS

Goals

The goals of this module are to:

- ▶ Offer participants an opportunity to reflect on what they learned during the session.
- ▶ Give participants an opportunity to offer feedback on the workshop.

Objectives

After completing this module, participants will be able to:

- ▶ Name at least one thing they will take away from the workshop.

Time

5-10 minutes total

Materials

- ▶ Clock
- ▶ Training Evaluation form

Module 4 - Activity A: Conclusion and Evaluations

Explanation

This activity is meant to conclude the training and give participants an opportunity to evaluate the session.

Preparation

Make copies of the evaluation form.

Procedure

1. Go around the room and ask participants to name one thing that they learned or that was important to them from the session.
2. ***Thank participants for their time, attention and participation during the workshop.***
3. Distribute evaluation forms and encourage participants to be honest about their experience.

Key Points

- Remind participants that this workshop is only the BEGINNING of the conversation. Encourage participants to talk to each other, their friends, counselors and others about health care issues and strategies.
- Acknowledge the hard work and valuable participation of workshop participants. The workshop could not have happened or been as successful without them!
- If possible, make yourself available for individual questions and comments after the workshop.
- If possible, provide additional local resources – such as a directory of local medical clinics, syringe access programs, medical vans, etc. – for participants to check out.
- Explain that the evaluation is very important to make future workshops even better.

WORKSHOP MATERIALS: GROUP EXERCISE WORKSHEETS

Drug User Perspective Scenario

Group A: You are a Drug User Going to the Doctor

Health Care Provider Scenario

Group B: You are a Doctor Getting Ready to See a Patient

Alternate Exercise Worksheet:

Role Play Scenario

Group A:
You are a Drug User Going to the Doctor

You are Regina, a 36-year old African-American woman. You are going to see a new doctor named Dr. Davidson at a local health care clinic that you went to a couple years ago.

You are going to the doctor because you have been having bad headaches and have been very tired. Also you haven't been to the doctor for a while.

A few more details:

- You were told that you have HIV two years ago and are **starting to think about starting treatment** for the first time.
- You've been on methadone for a year and **shoot cocaine regularly**.
- You have been **using drugs on and off for about 12 years**.
- You have struggled with depression in the past but are **not taking any medicine** for your depression right now because your Medicaid had been cut off. You just got your **Medicaid turned back on**.
- You are currently staying in a **shelter**.

Thinking As Regina:

- 1. Why might it be important for you to talk about drug use? Why wouldn't you talk about your use?**

- 2. What would make you trust the doctor more? What makes you trust him less?**

Group B:
You are a Doctor Getting Ready to See a New Patient

Your are Dr. Davidson, a 43 year old white, male Primary Care Doctor at a community health care clinic. You are preparing to meet with a patient for the first time today – she has been to the clinic before, but not for a couple of years and you did not treat her.

By looking at her chart, you know that she is an HIV+ African-American woman. The last time she came to the clinic, she had an abscess on her arm that was likely from injection drug use. You don't know if she is still using drugs.

A few more details:

- You have been working at the clinic for 5 years and **haven't had a day off in a month.**
- You have appointments scheduled for the entire day and will only be able to meet with your patient for **20 minutes.**
- You were supposed to see the same patient last month, but she **didn't show up** for one appointment and **came too late** to be seen for another appointment.
- You **don't know why** she is coming in today – only that she has been having headaches.

Thinking as Dr. Davidson:

- 1) Does it matter if your patient is using drugs now? Why or why not?**

- 2) What will make you trust your patient more? What will make you trust them less?**

Role Play Scenario

Act out a conversation between Regina, a drug-using patient, and Dr. Davidson, a doctor at a local health care clinic.

In this conversation, Dr. Davidson is asking Regina about her drug use.

Regina is unsure exactly how much she wants to say because she is worried she won't be treated the same if she is honest about her use.

Dr. Davidson is worried that his patient is using street drugs and that she might be allergic to something in the drugs.

More about Regina:

You are a 36-year old African American woman who is also HIV+. You came to the doctor today because you have been having serious headaches and are thinking about starting treatment for your HIV. You've been on methadone for a year and shoot cocaine regularly. You have been using drugs on and off for about 12 years.

More about Dr. Davidson:

Dr. Davidson is a 43-year old white male doctor. You are very overworked and haven't had a day off in a month. The patient you are meeting with, Regina, is HIV+, on methadone, and used to inject drugs. **You don't know if she is injecting now.** You were supposed to see Regina last month, but she didn't show up for one appointment and **came too late** to be seen for another appointment.

WORKSHOP EVALUATION

Please help us by taking a few moments to let us know how you felt about today's workshop. What you think is important and will help us to make the workshop better. Please circle your response below:

| | Poor | Fair | Good | Excellent |
|---|------|------|------|-----------|
| 1) How would you rate the workshop overall? | 1 | 2 | 3 | 4 |
| 2) How would you rate the facilitator overall? | 1 | 2 | 3 | 4 |
| 3) How well did the facilitator communicate information with the group? | 1 | 2 | 3 | 4 |
| 4) People were encouraged to share their opinions. | 1 | 2 | 3 | 4 |
| 5) Do you think the training will help you in your personal life? | 1 | 2 | 3 | 4 |
| 6) Was the facilitator knowledgeable about the topic? | 1 | 2 | 3 | 4 |
| 7) How well did the facilitator answer questions? | 1 | 2 | 3 | 4 |
| 8) What did you think of the workshop materials? | 1 | 2 | 3 | 4 |

TURN OVER – MORE QUESTIONS ON THE OTHER SIDE →

How much do you think the workshop will help you in getting better health care?

A great deal A lot Not much Not at all

Would you recommend this workshop to others?

Yes – definitely! Maybe No

What were the most important things you learned in the workshop?

What did you like the most about the workshop?

What would you change about the workshop?

Do you have any other thoughts or suggestions?

THANK YOU VERY MUCH!

Quality Health Care Is Your Right!

→ **A Guide for Drug Users
to Getting Better
Health Care**



A PUBLICATION OF THE
HARM REDUCTION COALITION

**This booklet has been written for
drug users in order to make going to
the doctor and getting other kinds
of health care easier.**

It's totally ok to be scared or nervous about going to the doctor or to not know what to say when you get there. It even makes sense if you just don't want to go, even when you know you probably should. You are not alone in *feeling that way*.

Going to the doctor can be stressful and is really no fun when you don't feel well. It can be even harder if you use drugs and/or have had a bad time at the doctor before. Prejudice and judgment around drug use can lead to being treated differently by doctors and medical staff. This shouldn't happen—but it can. But, there are lots of good, caring people working in health care who will care about you, your needs and your health.

Your health is very **IMPORTANT!**

You DESERVE to get good, quality health care—it is your **RIGHT!!**

This pamphlet is meant to give you some tips that will make getting good healthcare a little bit easier.

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Why Go to the Doctor

- Going to the doctor can be stressful. Doctors may tell you things you don't want to hear and are expensive. For drug users, there's added stigma and fear of being mistreated. So, then why go? Here are some reasons:
 - If you have an infection or serious medical problem it can get worse without medical care.
 - If you have a long-term illness, it is good to keep track of how you're doing so that you know your options and can make smarter treatment decisions.
 - To get medicine.
 - To stay healthy and to avoid future problems.

When to Go to the Doctor

- If you have a problem or concern about your health, it is best to go to the doctor early. *It is much easier to find a doctor when you don't need one!*
- Long waits feel longer when you don't feel well.
- If you see a doctor when you don't feel sick, you may be able to find a problem before it gets more serious.
- If your doctor knows you, you may get seen faster when you really need to.
- After you and the doctor get to know each other, it may become easier to talk about issues like drug use.
- By finding a doctor before you get sick, the doctor knows that you care about your health.

Where to Go for Health Care

- **Where are you already getting services?**

Methadone programs, outpatient programs or other clinics may have health care services available also. Places where you already get good services may also be able to help you find good doctors.
- It may (or may not) be easier to talk about drug use in places where you already get services.
- **General Health Care Clinics/Community Health Centers**

Health care centers are good for routine care, and more serious things when emergency care isn't required.
- You should be able to see the **same doctor** for each visit and you can usually take care of many different medical needs in **one location**.
- Staff will get to know you and you may not need to give a detailed medical history each time.
- Some clinics will have a **sliding scale** for payment and/or take **Medicaid**. Public health centers must treat you even if you don't have insurance and will decide how much to charge based on your income.
- If you have internet access, find a health center near you at this link: <http://findahealthcenter.hrsa.gov>. In NYC you can also call 311.

- **Hospital Emergency Rooms (ERs)**

It is best to use the ER only in an emergency. If it is not an emergency, it is better to go to a community health center.

If you're having an emergency, ERs MUST treat people even if they can't pay. When it is not an emergency, you may not get much help.

If you don't have insurance and you have to go to the ER, your best bet is probably to go to a **public hospital**.

The public ER may be able to help you get rid of lice, scabies or other related pests. *This may not be considered an emergency, so you may have to wait longer.*

ER doctors may be able to give you referrals to other services you need.

You may have a **very long wait** at the ER.

More about Emergency Rooms

The ER is not the best place to go for health care that is not an emergency.

Here are some reasons why not:

You might not get the best care when it isn't an emergency.

It takes a lot of time because doctors need to be able to take care of serious emergencies.

ER staff are often over-worked and may be stressed out. This may affect the way they talk to you and the **level of attention** you get.

- **Syringe Access Programs (SAPs)**

SAPs are also known as syringe exchange programs (SEPs) or needle exchange programs (NEPs).

SAPs work with drug users all the time. They should be less judgmental and know more about drug-related health issues. Some SAPs will have social workers, case managers or counselors that can help you to find services, make appointments, apply for Medicaid/benefits and even keep copies of important records. Some may even offer healthcare.

- **STI Clinics**

Special care and testing for sexually transmitted infections (STIs), including HIV, and some provide hepatitis C testing.

May offer free testing and services, including medication if you cannot afford it.

- **Mental Health Clinics**

Specialized care for mental health with therapists, social workers, counselors and psychiatrists.

It is important to find someone you trust when you talk about your feelings and emotions. If you don't feel comfortable with someone, it is ok to ask to talk to someone else.

- **Immunization Clinics**

You can get important vaccines for things like hepatitis A, hepatitis B, tetanus and the flu.

- **Infectious Disease Clinics**

Offer special care for things like HIV, HCV, STIs, and TB. May be more understanding to the needs of drug users.

- **Dentists**
You may find good dentists at clinics that are part of dental schools; they can be much **cheaper** and because the dentists are **learning**, they might work harder to impress teachers.

When using Medicaid, a lot of dentists are more likely to pull your teeth than to give you a root canal. Ask around for dentists who might be more willing to work with you.

Try and get the medical student with the most experience—don't be afraid to ask. Some schools even have graduate students.

Paying for Your Health Care

Having health insurance before you get sick will mean more choices when you need them.

Medicaid: a program for New Yorkers who can't afford to pay for medical care.

Medicare: a health insurance program for people over 65 or for people with certain disabilities.

AIDS Drug Assistance Program (ADAP): a program to help people with little or no insurance pay for HIV/AIDS medications. ADAP is not available to people with Medicaid.

There is almost always a wait before health insurance (Medicaid or other health insurance) gets turned on.

- Do your best to go to any meetings with your worker and complete requests from Medicaid. It can be a problem if your benefits get cut off. You might even stop getting medicine that you need.

If you don't have insurance, look into public health insurance programs and clinics that might have a sliding scale. You might be able to get Medicaid to pay bills that you got while you were waiting for your Medicaid to get turned on.

- **Medicaid and HMOs**

If you get Medicaid, you will probably have to pick a Medicaid managed care program or "HMO" (Health Maintenance Organization).

If you are homeless or have serious mental illness, you might be able to get straight Medicaid and **not have** to pick an HMO.

If you do not choose one, Medicaid *will pick one for you*. You have 90 days to pick an HMO.

When you pick an HMO, it means that you must go to a doctor or clinic that is *in that HMO* every time you need medical care. You will **not** be able to go to just any doctor. If you need something special, you will need to get a referral from your doctor.

You CAN change your HMO, but it is not easy. You don't have to give a reason for changing during the first 90 days of being placed in an HMO. After 90 days, you have to give a reason if you want to change, and only a few, specific reasons are accepted.

- **Medicaid and HIV SNPs**

If you are HIV+ and get Medicaid, you can choose an HMO or an HIV **Special Needs Plan (SNP)**.

An HIV SNP is a health plan that covers the same services as a Medicaid HMO, but also covers other special services that are important to people living with HIV.

When you choose a SNP, you will still have to go to a doctor in the plan, but HIV SNP doctors are "HIV specialists."

Tips for Finding a Good Doctor/Provider

Ask around: Get referrals from other drug users, friends, family, co-workers, counselors, and people you trust. Find out what people like best about their doctor and about any strategies they've used to find good healthcare.

Shop around: Going to a couple of doctors before you find one you "click" with is normal. It might feel like a hassle at first, but in the long run, it can be worth it.

Think about when you choose a dealer—you probably try a couple until you find the one with the best product, is available when you want them, you feel safe with and who you can trust. You may need to go to others in a pinch, but it's good to have a first choice.

IF YOU LIVE IN NYC, YOU CAN CALL

1.888.692.6116 for questions about Medicaid and 1.800.505.5678 with questions about HMOs and HIV SNPs.

For replacement Medicaid cards, call the HRA hotline at 1.877.472.8411.

Outside NYC, you can call your local Department of Social Services. If you need help, ask your provider.

For more information about ADAP, call 1.800.542.2437, or visit www.nyhealth.gov.

For more information about Medicaid, call 1.800.633.4227, or visit www.medicare.gov.

Consider location: How easy is it to get there? Are you comfortable going to a doctor in your neighborhood?

You may be able to get many services in one location. Check to see if you can get carefare for your visit.

Consider hours that the doctor is available or the clinic is open: Do the hours fit your schedule? Hospitals and hospital-based clinics may have more flexible hours. Make sure the doctor and her/his staff speak your primary language—communication is important!

Consider how you feel about the entire staff at the office or clinic you go to—they are all part of your health care.

You have a right to stand up for yourself and change doctors if you want to. Your medical records should not be shared without your consent (unless it's an emergency).

How to Prepare for Health Care Visits

- **Think about your main reason for going to the doctor and what you want to get from the visit—stay focused.**
- **Take care of any drug use needs before the appointment.**

Schedule appointments when you won't be in withdrawal. This will help you focus on the visit and won't distract the doctor from any other health care needs you may have.

If you show up for your appointment too high, it is likely to have a negative impact on the care you get and the doctor may ask to reschedule.

- **Make a list of questions you have for the doctor.**
- You may not get to all of your questions. Mark the things that are most important to you.

Scheduling Appointments

Schedule visits for a time when you are most likely to make it.

Find out if you need to make an appointment or if the clinic has drop-in hours.

You might get better care in the morning or mid-day. If you come right before closing people might be thinking about going home!

Asking to get the first appointment of the day, or the first appointment after lunch might cut down on wait times.

Write down your symptoms.

Include what the symptoms are, when they started, how often you have them and how severe they are on a scale of 1 (not very painful)–10 (the MOST painful). Be realistic.

- **Make a list of medications that you are taking and other doctors that you are seeing.**
- Include prescribed medications as well as over-the-counter medicines, supplements and herbal treatments.

Bring someone with you when you go to the doctor.

It is good to have someone to keep you company, to help advocate for you and to show the doctors that you have support.

- **Do your best to be on time (or even early) for the appointment.**

Arrange transportation and/or money for transportation to and from your visit ahead of time.

If you think you might be late or have to cancel your appointment—call the office and let them know as soon as you can.

- **Make sure you have your IDs and/or medical insurance card (if you have one) ready to bring with you.**

It's always a good idea to keep copies of all of these documents.

What to Expect When You Get There

There may be a long wait.

- Try to plan ahead so you don't go into withdrawal while you're waiting. Bring something to do while you wait (something to read, crossword puzzles, etc.).
- You can also use this time to think about and write down questions or things you want to talk about with the doctor, if you haven't already.

You may talk to several nurses and other staff before you see the doctor. Be patient and consistent if you have to explain things more than once. They are trying to help and need to hear information directly from you.

You may have to fill out some paperwork—it's ok to ask for help, and to ask for paperwork in the language you understand.

Your time with the doctor may be very short and s/he will probably only address 1-2 problems at a time.

Doctors are often overworked, may be in-training, and may be distracted. It is not unusual for doctors to answer the phone while you are with them.

- Even though it can be frustrating, doctors may treat you with more patience if you are patient with them.

You may be asked to talk about sensitive issues with other people very nearby—especially in the ER. If you need privacy, it is ok to ask for it (although you may not always get it).

- **Identification (ID)**

Most health care clinics will require that you have one or more forms of identification (ID) such as a state driver's license or ID card, passport, military ID, etc.

It is best to give your real name, but if you are worried about it, you can get some help at the ER even if you don't have ID or give your real name.

It is better to say you don't know than to give a fake social security number.

If you are admitted to the hospital, you will probably have to give real information for billing and medical record purposes.

You will be asked questions about your medical history and current health, including drug use (and the health of your family).

- Think about what you feel comfortable talking about so that you are not caught off guard.
- Doctors use this information 1) to help give you the right diagnosis and 2) so that they do not prescribe medication that is unsafe. But, sometimes what you tell them will change the way you are treated. It is important to think about how and when you want to talk about things like drug use before your visit.

Talking with Health Care Providers about Drug Use

Drug use is a personal thing. Even though it may not always feel like you have a choice, it should be up to you when and how much you talk about your drug use, even with doctors. Here are some things to think about when deciding how to talk about drug use with your medical providers.

- **Reasons why it may be hard to talk about drug use (and why some people decide not to):**

Doctors may treat you poorly because of ideas they have about drug users instead of getting to know you as an individual.

Doctors may focus only on your drug use, instead of taking care of what you want help with. If you can talk about your

symptoms without talking about drug use—that may be enough.

Doctors prescribe medication differently to people who use drugs.

You have likely had a bad experience talking about drug use in the past.

- **Some reasons why it is good to talk about your drug use:**

The doctor may be able to make a better diagnosis if s/he knows the whole story. Even symptoms that may seem unrelated to drug use can sometimes be a result of drugs you are taking or the "cut" in those drugs.

There may be interactions between drugs you are taking (street, prescription or over-the-counter) and medications that the doctor wants to prescribe.

If the doctor finds out that you are using drugs (through tests or in another way) without you telling them first, they may lose trust in you.

It is important to be honest with yourself about your drug use.

Because drugs affect your body and health, sometimes it's important to talk about them.

BUT – If you don't want to talk about your use, that is your right.

If your doctor doesn't respect your boundaries, or makes you feel uncomfortable when you talk (or don't talk) about drug use, s/he may not be the right doctor for you.

- **If you decide to talk about your drug use:**

It's ok to build trust first. If you need to, wait to talk about your drug use at the second or third visit.

Be polite and keep an open mind—don't expect the worst.

- **If the doctor is focusing too much on your drug use:**

Politely remind them about the issue you are asking for help with.

Ask the doctor to explain how your drug use is related to the issue you are asking for help with. If you disagree, explain this to the doctor in a friendly way—or find a new doctor.

Here are examples of things you can say to the doctor when you don't want to talk about drug use:

"I hear what you are saying and maybe we can talk about my drug use later. Right now, I am more worried about _____."

"I understand that you are worried about my drug use but I am not ready to change that. I still care about my health and would like your help with _____ now."

"Can you explain exactly how my drug use will impact _____? I do want to feel better, and I don't want to change my use right now. Maybe there are some other things I can do now?"

"If I can't change my drug use right now, are there other things I can do to take care of my health? Maybe then we can start to talk more about my drug use."

Tips for Communicating with Your Doctor

Your relationship with your doctor does matter—it's great when you can work as a **team**. If you're not comfortable with your doctor—consider finding someone new.

If doctors, nurses, or other staff don't speak your language, you have a right to a **translator**.

Ask **questions** until you understand. It's ok to ask for simpler answers. You have a right to understand your health care.

Be as honest as you can be. If you can't talk about everything right away, it's ok.

Be patient with your doctor—just as you want them to be patient with you. Remember that they are **only human** too and have good and bad days.

Stand up for yourself in a polite way. You can be **firm**, and still be **friendly**!

Trust yourself. If you think that the doctor is ignoring something important—ask questions. This can be hard, but in the end, your health is worth the extra effort.

Be careful about getting angry or defensive. Anger or aggressiveness will probably make the doctor stop listening and try to end the visit quickly.

You know best what will and will not work for you. Talk to your doctor if you think s/he is making an unrealistic plan for you so that you can try and come up with a better plan. This is very important when it comes to taking your medication as it is prescribed.

Take notes or ask the doctor to write down important things for you. It can be hard to remember everything.

Give positive feedback when things go well—let doctors know when they get it right!

Things That May Have a Negative Impact on Your Health Care

- Answering your cell phone or texting during a visit.
- Even though things might be frustrating, being rude or aggressive is rarely helpful. It may make nurses, doctors, or other staff want to help you less.
- Missing appointments without calling ahead of time or canceling many appointments in a row.
- **Saying that your pain is much worse than it is.** The doctor may give you the wrong diagnosis, or order more tests than you need. It may also take time away from other people who might need more help than you—this can make doctors angry.
- **Not getting tests** that the doctor schedules for you. This may make them get frustrated and lose trust.
- **Telling the doctor what your diagnosis should be.** Doctors and nurses don't want to be told what their job is or how to do it. But, if you have had the same kind of problems in the past, it could be helpful to share the information with them.
- **Selling your medicine.**

Before You Leave and After the Visit

- **Schedule a follow-up appointment before you leave the office.**
- Get the office to write down the information on an appointment card that includes the date and time of the visit, along with the phone number and address of the office.
- If you have a phone, ask the doctor's office to give you a reminder call before the appointment.

IMPORTANT

Whenever you see a doctor, ask for copies of any test results, procedures, referrals or medications given. These are part of your medical record. If you want copies later, you might be charged money to get them, they can be hard to get and it can take a long time.

Keep copies in a safe place where you will be able to find them later. If you don't have a place to keep them, ask someone you trust (friend, case manager, drop-in center, etc.) to keep the copies.

- **If your doctor refers you to a specialist—it is important to follow-up.**

If the referral came from an ER doctor, it is probably even more important to follow-up so that you don't end up back in the ER for the same thing.

If things don't work out with the specialist, go back to the doctor who referred you so that s/he can keep trying to help you.

- **Make a list with the dates of referrals, future visits, any tests that were run and any test results and any new medications you received.**
- **Ask about any potential side effects if you are given medication and how to make them easier to deal with.**

Tips for Taking Your Medicine

Get a pill case—the kind with a little box for each day of the week. They can be found at drugstores.

Many people have found that getting on methadone or buprenorphine is helpful when they need to take other medicines on a schedule.

Ask someone you trust to hold the medicine if you think you might lose it. They can also remind you to take it when you need to.

Find a pharmacy that is close to where you stay or cop drugs so it is easy to fill your prescriptions.

If you take street drugs every day, you could use coping as a reminder to take your medicine.

Talk to your doctor about your schedule (what time you wake up and go to sleep) and when it would be best to take your medicine.

Find out if your medication needs to be taken with food or on an empty stomach.

Ask your doctor what will happen if you drink alcohol while taking your medicine. It may not be a problem to take your medicine AND drink—it is better to ask your doctor than to stop taking your medicine. Some medicines (like anti-depressants) will make you feel drunk faster though—so be careful.

SPECIAL ISSUE:

Pain Management

Asking doctors for help with pain can be a very sensitive issue. Some people who use, or have used, drugs will have trouble getting the pain medicine that they need to be comfortable. Others may not want certain pain medicine because of their relationship to addictive drugs.

A lot of doctors treat drug users differently when it comes to pain management. Finding the best way to address pain will depend on your specific issues and your relationship with your doctor.

Some things to keep in mind:

Keeping a "Pain Journal" is very helpful!

Write down when, where and how much pain you have...the more details the better.

Keep track of exactly how the pain is **changing your daily activities**. For example, if the pain is keeping you from sleeping, working or eating.

Include anything that has **helped you feel better** OR made the pain worse. For example, over-the-counter medication, heating or cooling the area, walking, kneeling, resting, etc.

Don't ask directly for pain medicine **right away**—give it some time and let your doctor make suggestions.

Letting the doctor know that you are open to trying **non-opioid/non-prescription solutions** to pain is important. For example, things like acupuncture, physical therapy, meditation, etc.

Suggest only getting small prescriptions for pain killers at a time. For example, have your doctor prescribe you enough pills for one week at a time.

If you do not want to take opioids because you are concerned about **relapse or cravings**, be honest with your doctor so that you can work together to think of other options.

If you are admitted to the hospital, you may want to re-think a choice not to talk about drug use. They will probably figure it out from the test results, and you may be more comfortable if you share the information.

Be Careful with Common Pain Relief Medicines!

It is important to talk to your doctor if you are taking Tylenol (acetaminophen). Acetaminophen can be more serious than you may think...and it is common in many cold medicines and pain medicines (Percocet, Vicodin, Ultracet, etc.).

Too much acetaminophen can cause **very serious liver damage or liver failure**. That means no more than 4 grams or 4000 milligrams or 8 tablets of Extra-Strength Tylenol a day and be careful when you take it every day for a long time.

Drinking alcohol on top of high doses of Tylenol can be damaging to your liver.

Ibuprofen (Motrin, Advil) and Naproxen (Aleve, Midol) should be taken with food to avoid stomach ulcers.

It is not safe to take more pain relief medicine than the bottle tells you.

SPECIAL ISSUE:

Methadone

Tell your methadone clinic or doctor if you start taking new medication. Some medicines can make your body process methadone slower or faster, meaning **your methadone dose may need to change if you start taking new medications.**

If you are on methadone, you may have been told that you cannot take "Talwin." This is true, but you should also know that **Talwin is not used much anymore.** So, if you tell a doctor you can't take it, you are basically telling them that you are on methadone.

It is important to talk to your methadone program about medications prescribed to you—especially if they might come up in your urine. **Bring the bottles to your appointment if you can.**

Reproductive Health and Pre-natal Care

It is important for women to visit the obstetrician/gynecologist for **regular exams**—even if you are not getting your period.

If you are pregnant and using drugs, **prenatal care is VERY important** for you and your baby's health.

When a woman does not go to prenatal care, the hospital where she has her baby may consider this to be neglect and may call children's services (CPS or ACS).

Women who do not seek prenatal services may be more likely to be **drug tested** at delivery.

PARENTS: It is possible for a doctor to report you to children's services if they think your child or children aren't getting the best care. Sometimes (not always), just using drugs can make a doctor question your parenting.

SPECIAL ISSUE:

HIV and Hepatitis

- **HIV/AIDS:** If you're HIV+ or have AIDS, it is best to find a **specialist** in HIV/AIDS (usually called an Infectious Disease doctor). They are more likely to have up-to-date information on medical treatments.

It is very important to take HIV medicines **exactly as they are prescribed.** If you do not, the virus can figure out ways to make the medicine stop working (called resistance).

There is **extra public assistance** (including medical insurance) for people living with AIDS in New York State.

Hepatitis C: Hepatologists and many gastroenterologists are **liver doctors** who will know more about hepatitis C virus (HCV) than general doctors, but some tests for HCV can easily be done by a regular doctor.

There are **medicines to treat HCV**, but not everyone with HCV needs them. Ask your doctor.

Some people can fight hepatitis C without medicine. It is possible to have antibodies for HCV (meaning your body's immune system remembers HCV) and to **not actually have HCV anymore.** Ask your doctor for more information.

Unfortunately, many doctors still do not make it easy for people who still use or inject drugs or drink to get HCV treatment.



SPECIAL ISSUE:

Drug Treatment

Some drug treatment programs have medical care on-site.

There are many different kinds of drug treatment programs, both inpatient and outpatient.

It is important to find a drug treatment program that will **support your needs**. Try and find out exactly what kinds of groups and services are offered.

Calling programs before you go can give you a better idea of what to expect. For example, most (if not all...) inpatient programs don't allow cigarette smoking.

Your insurance may only pay for you to go to certain kinds of drug treatment, or it may limit the **number of times** that they will pay for you to go to treatment within a certain time period. For example, if you leave a 28-day program early, you may not be able to go back again for a **certain period of time**.

Some treatment programs **require that you complete a medical detox** before you can enter their program. This means that they cannot take care of you if you are in withdrawal.

SPECIAL ISSUE:

Mental Health

Mental health services can be accessed at some syringe access programs, community-based organizations, general health clinics and the ER.

The ER can help with mental health issues, but only if they require **immediate attention**. *If you are thinking about hurting yourself, go to the ER or call 911.*

If you are waiting for your Medicaid or insurance to kick in, ask your psychiatrist if they can get "samples" or help with **patient-assistance programs** (drug company programs where they give medication to people who need it, but can't pay for it).

If you take benzos (like Xanax, Klonopin, Librium, etc.), be very careful when you stop taking them for a period of time. **Coming off benzos too fast can cause seizures.**



HARM REDUCTION COALITION

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The Harm Reduction Coalition is a national advocacy and capacity-building organization that promotes the health and dignity of individuals and communities impacted by drug use. HRC advances policies and programs that help people address the adverse effects of drug use including overdose, HIV, hepatitis C, addiction, and incarceration. We recognize that the structures of social inequality impact the lives and options of affected communities differently, and work to uphold every individual's right to health and well-being, as well as in their competence to protect themselves, their loved ones, and their communities.

Produced with support from the New York State Department of Health AIDS Institute.

design:workright

SELECTED READINGS

List of OASAS providers that will serve pregnant women

Bad Attitudes in the ER: It's a Two-Way Street. Flynn, *Harm Reduction Communication*, Summer 2000.

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Advice from an ER doctor to drug seekers. Anonymous, Best of Craigslist, SF Bay Area, 2007.

Mutual Mistrust in the Medical Care of Drug Users: The Keys to the "Narc" Cabinet. Joseph O Merrill, MD, MPH, Lorna A Rhodes, PhD, Richard A Deyo, MD, G Alan Marlatt, PhD, and Katharine A Bradley, MD, MPH, *Journal of General Internal Medicine*, 17:5 (2002) 327-333.

12 myths about HIV/AIDS and people who use drugs. Chris Beyrer, Kasia Malinowska-Sempruch, Adeeba Kamarulzaman, Steffanie A Strathdee. *The Lancet*, 376:9737 (2010) 208-211.

Home Programs Addiction Treatment Centers (ATC)

OASAS ATC Directory[Directory in plain text.]

| Name | Address/Phone | Catchment Area |
|-----------------------------|--|--|
| <u>Russell E. Blaisdell</u> | Rockland Psychiatric Center, Bldg 57 Box 140 Orangeburg, NY 10962-1129 845/359-8500 | Columbia, Delaware, Dutchess, Greene, Orange, Sullivan, Ulster, Putnam, Rockland, Westchester |
| <u>Bronx</u> | Bronx Psychiatric Center, Bldg 13 1500 Waters Place Bronx, NY 10461-2723 718/904-0026 | Bronx |
| <u>Creedmoor</u> | Creedmoor ATC Building #19 - CBU 15 80-45 Winchester Boulevard Queens Village, NY 11427 718/264-3740 | Queens |
| <u>Kingsboro</u> | 754 Lexington Avenue Brooklyn, NY 11221 718/453-3200 | Kings |
| <u>McPike</u> | 1213 Court Street Utica, NY 13502 315/ 738-4600 | Albany, Chenango, Columbia, Fulton, Greene, Herkimer, Madison, Montgomery, Oneida, Ostego, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington |
| <u>John L. Norris</u> | Rochester Psychiatric Center 1111 Elmwood Avenue Rochester, NY 14620-3005 585 /461-0410 | Genesee, Livingston, Monroe, Orleans, Wyoming Statewide for Deaf and Hard of Hearing |
| <u>Charles K. Post</u> | Pilgrim Psychiatric Center Campus Building #1 998 Crooked Hill Road West Brentwood, NY 11717- 1087 631 /434-7200 | Nassau, Suffolk |
| | | Albany, Clinton, Essex, |

| | | |
|--|--|---|
| <u>St. Lawrence</u> | Hamilton Hall One Chimney Point Drive Ogdensburg, NY 13669-2291 315/393-1180 | Franklin, Hamilton, Jefferson, Lewis, Rensselaer, St. Lawrence, Saratoga, Schenectady, Warren, Washington |
| <u>South Beach</u> | South Beach Psychiatric Center Building A 777 Seaview Avenue Staten Island, NY 10305-3499 718/667-5202 | Richmond |
| <u>Margaret A. Stutzman</u> | 360 Forest Avenue Buffalo, NY 14213-1205 716/882-4900 | Allegany, Cattaraugus, Chautauqua, Erie, Niagara Statewide for Native Americans |
| <u>Dick Van Dyke</u> | 1330 County Road 132 Ovid, NY 14521-9716 607/869-9500 | Broome, Cayuga, Chemung, Cortland, Onondaga, Ontario Schuyler, Oswego, Seneca, Steuben, Tioga, Tompkins, Wayne, Yates |
| <u>Richard C. Ward</u> | 117 Seward Avenue Bldg. 92, Suite #12/16 Middletown, NY 10940-6198 845/341-2500 | Columbia, Delaware, Dutchess, Greene, Orange, Sullivan, Ulster, Putnam, Rockland, Westchester |

Bad Attitudes in the ER: It's a Two-Way Street!

BY NEIL FLYNN, ILLUSTRATION BY SUN JENSEN



This article is a presentation made by the author to Emergency Room physicians, residents, and interns at the University of California, Davis Medical Center and at the Heroin Overdose Prevention Conference in Seattle, January 2000. The ideas presented in this article are more conceptual and come from personal observation rather than empiric data. The ideas evolved naturally from Knowledge, Attitude, and Behavior (KAB) work with drug users and 25 years of experience as a health care provider.

The Problem—Health Care Providers

Health care providers often hold negative, stereotyped beliefs about drug users, beliefs which influence attitude as well as care. Drug war rhetoric has had a significant affect on health care providers, in spite of mounting scientific, medical and public health evidence to the contrary. There is widespread ignorance of the data supporting harm reduction approaches to care, and an absence of harm reduction curriculum in medical training and Continuing Medical Education (CME) programs. Often these beliefs are based on bad experiences with individual drug users, and on personal use of drugs, rather than on medical/scientific knowledge; the better health care providers personally know their drug-using patients, the more positive their attitudes toward drug users are.

The Problem—Drug Users

Drug users, who often expect to be treated poorly by emergency medical technicians (EMT) or emergency room (ER) staff, frequently appear to have "a chip on their shoulder." These attitudes result from prior negative experiences with health care providers. Users are often in a great deal of pain when they seek treatment, and are irritable. In addition, there is a fear of exposure of their drug use to family, friends and employers—not to mention their health insurance provider. There is also the possibility that they will be turned over to the police by hospital workers (and arrested and prosecuted), should they have any drugs in their possession. Drug users are estranged and marginalized from the non-drug-using society, and frequently have un-addressed mental health issues. All of these issues contribute to the poor patient-provider relationship that develops.

The Survey

We conducted a brief, rather informal survey of 22 ER health care providers in Fall, 1999 regarding their KAB about drug users. They were presented with several statements, prior to a harm reduction talk, and asked to agree or disagree. The percent of those who agreed with each statement is in bold text following the sentence. The results follow:

Drug use (other than alcohol) per se is bad. This includes marijuana, opiates, cocaine, methamphetamines and hallucinogens—**36% affirmative**. This response suggests to me that harm reduction is a concept that might find fertile soil among emergency care providers.

People who use drugs other than alcohol deserve to go to jail—**0% agreed**. This response is even more heartening.

Sending people to jail for drug use is more effective in dealing with the problems of drug use than is any other use of taxpayers' money—**0% agreed**. Once again we see

that ER staff may be potential converts to the harm reduction philosophy.

Most of the resources the U.S. devotes to addressing drug use are used for law enforcement—**14% affirmative**. We can introduce a little cognitive dissonance here by educating these providers that, despite the empiric evidence which supports alternative uses of our tax dollars, most of the money thrown at the problem lands in the law enforcement pocket—not the treatment pocket.

Public money would, in general, be better spent if a public health (disease prevention, health promotion) and medical model (drug treatment) rather than a criminalization model were to inform U.S. drug policy—**68% agreed**. If they only knew!

When drug users are difficult to work with in the ER, and on the hospital wards, the "blame" for it is mostly theirs—**45% agreed**. Over half recognize their own contribution to the problem. The great majority of these health care providers are people

of high intelligence and big hearts. *They need training and tools!*

Most drug users couldn't control their drug use and be productive citizens if they had unlimited access to their drug of choice (sterile, known potency), at reasonable cost—**36% agreed**. Here again we see that almost 2/3 of these health care providers have somehow heard, processed and agreed to some extent that drug users can be responsible for themselves, given opportunity.

Possible Solutions—Health Care Providers

- Improve health care providers knowledge of the various drug use cultures and drug use itself.
- Put a human face on drug users.
- Appeal to health care providers innate compassion and humanity—nothing hits us harder than to be accused of insensitivity and lack of compassion. It is our Achilles' heel!
- All levels of medical and nursing education should include more training on these issues. A concentrated effort to include principles of harm reduction in CME and basic training will pay dividends for harm reduction.

Health care providers need a better understanding of psychosocial aspects of drug use. Often times, mental health issues probably preceded drug use. In fact, drug use may be ameliorating symptoms. Many drug users were abused as children. Health care providers should call loudly for policy makers to provide for comprehensive treatment on demand.

Health care providers should also have a better knowledge of the pharmacology and effects of opiates, cocaine, methamphetamines and hallucinogens (most have tried marijuana). It wouldn't hurt to compare these drugs to alcohol and tobacco products for safety, potential for injury, abuse, etc.

They need better guidelines for judging analgesic needs of drug users as well as a better understanding of abstinence syndromes (withdrawal)—and proper alleviation of these symptoms.

Training should demystify drug users and debunk the myths surrounding them. Drug users are not asking to get or stay high in the hospital. Heroin users want to be as comfortable and free from pain as the person in the next bed, but this often requires a significantly higher opiate dose than for the non-habituated, and health care providers don't fully understand this.

Health care providers should examine their attitudes and "attitudes." Health care providers should be more hospitable and

feel free to use humor—"I'm sorry, but heroin isn't on the menu yet, may I offer you sustained release morphine or perhaps methadone?"

We must continue to point out the cruelty of the present system. We can give health care providers an alternate vision of drug users, with much of the violence, hostility, anger and self-loathing removed: we can call it "decriminalization." Shame on us for buying into and supporting the drug war—we (health care providers) should know better, leading the way to harm reduction.

After the session, the participants were asked, "Has this discussion changed your opinion of drug users in the ER in a significant way? **Four out of 22 (14%)** said yes. We will revisit these issues with ER staff in six months.

Possible Solution—Drug Users

Expose drug users to drug user-centered primary and secondary healthcare. Assertiveness training should be provided during drug user-centered healthcare, and in peer advocacy programs. Because every health care provider's contact with a drug using-patient is an opportunity to change minds, we need to get drug users on a mission to teach health care providers. At least half, or more, of drug users can become patient (double *entendre*) teachers of health care providers. After all, it is a two way street.

Summary

Although this was a small survey, and needs to be repeated on a larger scale, its results were not surprising. Health care providers have bought into the drug war as ordinary citizens and haven't applied their professional expertise to the problem. When they do they will think differently. More training is needed: make it the CME topic *du jour*. Drug users psychological reintegration into society will also go a long way toward improving professional and private lives of both drug users and health care providers.

Acknowledgements: I am indebted to the personnel of Harm Reduction Services, Sacramento, the talented group of research personnel with whom I work: (especially Ms. Rachel Anderson, Ms. Lynell Clancy and Mr. Jim Britton), and the many drug users who have, and will, undoubtedly, continue to teach me of our common humanity. ■

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WE WANT Y HRC M

Becoming a member of the Harm Reduction Coalition is one of the most significant ways you can support our organization's work and mission. As a coalition of harm reduction practitioners, providers, and consumers, HRC draws its strength, diversity, and expertise from the nationwide network—people and organizations like you—that is HRC. As a member, you will receive regular reports about HRC activities and events; a one-year subscription to *Harm Reduction Communication*; and discounts on HRC conferences, trainings, publications, and merchandise. So demonstrate your support of harm reduction and the Harm Reduction Coalition by becoming a member today.



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one junky's Odyssey

BY I THACA

I haven't had much experience in my life using health care services. The working class ethos under which I grew up dictated that folks take care of their own problems to the extent that they could: one needed to be *really* sick before a visit to a doctor or the emergency room was in order, and the idea of seeking professional help for mental health issues ("getting one's head shrunk") was even more outrageous, self-indulgent, and bourgeois. So, I never had a "family physician" or any kind of doctor I saw on a regular basis. Suffering stoically--but remaining in control of one's own body--was my family's *modus operandi*, one that prepared me well for my later life as a junky.

This past year, I made up for all those years I never saw a doctor. In August 1996, two days after returning from a six-week consulting trip to Eastern Europe, I found myself in the emergency room of a New York hospital, extremely weak and breathing only with tremendous difficulty. I was admitted, and, after a broncoscopy, diagnosed as having a life-threatening case of *pneumocystis carinii pneumonia* (PCP). Although I'd suspected for some time that I was HIV+, I'd never taken an antibody test. I was told that I had advanced AIDS (it turned out I had a whopping 15 T-cells) before I'd ever had the chance to grapple with what being HIV+ meant.

As someone who was closely involved in the original (illegal) efforts to establish needle exchange in New York City and having worked in one position or another as an advocate for the health needs of illicit drugs users for the past ten years, I was intimately aware of the incredible stigma, discrimination, and outright hostility and disgust injection drug users routinely face when attempting to seek health care services of any kind. Suddenly, I was my own client, and all of those years I'd spent advocating for other drug users, while giving me insight into some of the systems I would now have to negotiate for myself, did not prepare me for the treatment I would also receive as a heroin injector with AIDS.

While I had no unfounded expectations that things would be different or better for me than they'd been for so many of my former clients--why should they be?--nothing could've prepared me for the humiliation and emotional trauma I would experience over the next year as I tried simultaneously to deal with the fact that I had advanced AIDS, cope with a body that was quickly deteriorating (I've been hospitalized six times since the beginning of 1997), and, after years of hiding my own heroin

use from colleagues, acquaintances, and even my closest friends, end my life of duplicity and begin the process of coming out as a junky both in the public context of my job and the harm reduction movement and in my private world composed of those to whom I looked to and relied on for support in my personal life. The journey I've taken this past year as I tried to find appropriate health care--now literally a life-and-death necessity for me--has been a textbook case of how *not* to effectively engage illicit drug users in health care services. I share my story in the hopes that it will illuminate why harm reduction is so critical to reaching the population of which I now find myself a member.

When I landed in the hospital with PCP I had no physician of my own and, since I was working as a consultant, no health insurance of any kind. A doctor at the hospital where I was admitted luckily (I thought) agreed to take me on as a patient during my stay. I was maintained on methadone tablets (Dolophine) and pumped continuously with intravenous antibiotics for the treatment of the pneumonia. Although all the toxic drugs made me incredibly sick, I was relieved that I had connected with a doctor willing to care for me. My relief soon dissipated, however, when he stopped coming to see me and began to refuse my telephone calls (I would call his office and hear him in the background tell his secretary to say he wasn't in). After several days of unsuccessful attempts to simply get him on the phone, I was infuriated at being ignored, removed my I.V., and checked out AMA (against medical advice) under the hostile glare of several residents and nurses. My doctor was furious when I showed up at his office in order to get prescriptions to continue to treat my pneumonia (I learned later that my case was apparently serious enough that I should have been in the hospital for several more weeks of intravenous therapy). The explanation I received was that he was concerned I would engage in "drug-seeking behavior" if he let me out of the hospital (he actually used those words!); his treatment strategy was to keep me chained to a hospital bed until the PCP was completely cured.

After he wrote me prescriptions for Bactrim, prednisone, acyclovir, and the other pharmaceuticals I needed, I began to ask, "Would you give me a prescription forS" but before I could finish my sentence he shot back, his voice brimming with hostility, "I can't give you methadone. You'll have to go Beth Israel for *that..*" He was convinced that the only reason I'd come to his office at all was *not* to get the PCP treatments I needed but to scam him for a methadone script.

The clinical decisions he made about my care were clearly influenced by his personal beliefs about what junkies supposedly do, even though I had been a model patient interested only in recovering from the PCP and frankly too sick to be running around looking for drugs. His condescending, infantilizing treatment of me was unbearable, but I was the one who looked like a non-compliant, "drug-seeking" dope fiend when I checked out of the hospital because I wouldn't stand for it.

."You smoke?", the emergency room intake nurse wants to know. After answering a barrage of questions about one's health status and history in the ER, the same questions are again put to patients by another intake nurse once one gets to the floor, and then again by the admitting physician or resident. "No, never have," I say. "Wouldn't dream of poisoning my body that way."

"Drink?" "I used to drink heavily but don't anymore. Haven't really touched alcohol for the past year." I'm starting to look like a goody-two-shoes, completely pure in body.

I can tell the nurse asks the next question only because she's required to and not because, given my answers to the previous ones, she expects there to much in the way of illicit drug use going on with me.

"Well, uh, I, uh, shoot um, inject, you know, dope, uh, heroin." Despite the fact that I long ago mastered proper injection technique, I've always bruised profusely, and it seems, permanently. Track marks squirrel up and down the veins on both of my arms, upper and lower, like pictures from an anatomy textbook or tattoos. If I decided to lie about shooting dope, I'd be caught the instant someone went to take my blood pressure or plant an I.V.; besides, I have to let the hospital staff know that I'll need methadone if I'm going to be admitted. In the complicated calculus a junky employs when deciding how to answer each of these questions--a calculus used to try and determine what answer will bring the least amount of reprisal, discomfort, and shame--I figure it's better to be branded a plain old junky than a junky who lies.

I've been fortunate, I suppose, in that I've always felt pretty much in control of my drug habit. After a lifetime of depression, and long bouts of self-medicating with alcohol, cocaine, and whatever else was available, heroin was a godsend. In fact, I can truly say that junk is one of the best things that's ever happened to me. People are always telling me--including my doctor--that anti-depressants would work just as effectively and I wouldn't have to shoot up or involve myself in an illegal economy. All I know is that dope has worked and continues to work for me: it helps me wake up in the morning and go to sleep at night; have an appetite and digest my food properly (not an insignificant thing for a PWA); get through a day without feeling crushing depression; enable me to get to work and be productive in a very challenging job; control the horrible diarrhea I get as a result of taking toxic medications; manage the diffuse pains I experience that I'm told are caused by HIV attacking my muscles and joints; and, contrary to the stereotypical images of junkies nodding out in doorways, junk gives me huge amounts of physical energy and the motivation to get things done. This is not to say that my heroin career has always been easy or problem-free. Believe me, I know the dread of waiting for withdrawal to set in after you've shot your last bag and are out of money. I know what it's like chasing down dope in the dead of winter (that blizzard we had in '95 was a bitch!); buying drugs from asshole dealers; and spending one's last \$20 on two beat bags. Using is not a complete bed of roses for anyone, and I am no exception, but the positives still outweigh the negatives for me, and always have.

My heroin use has always played a very functional role in my life, primarily as a means for coping with depression, and perhaps it is this conscious awareness of why I use that's enabled me to never really be scared of junk or afraid that my habit would become so out of control that I'd end up, literally, in the gutter. My passionate belief in the efficacy of harm reduction--borne out again and again by my personal experience--has allowed me to use successfully and confidently, for the most part, and in ways that are beneficial to me instead of harmful. I do not buy into the idea that eventually I will hit some "bottom" and finally come to my senses. Using does not have to entail despair, misery, and heartache

There have been times when admittedly my habit's gotten out-of-hand with miserable results (including just recently), but largely I've been able to slow down or stop using when I've needed to.

While detox and withdrawal are never easy or enjoyable, a gradually-decreased, three-to-five day course of Dolophine (which my new doctor used to prescribe for me) would usually get me through if I needed to take a break or travel for work. At other times, I'd shoot coke for three or four days to get through a jones (something I refrain from doing these days because of my health) or just go cold-turkey and suffer through it.

Earlier this year I learned that detoxing is much harder to do with 15 T-cells and virtually impossible when you're on rifampin for tuberculosis treatment and the anti-seizure medication Dilantin, both of which cause the liver to metabolize methadone at outrageous rates.¹ The longer I was on rifampin, the more efficient it became at clearing methadone from my body until at one point, 90 milligrams was lasting me only about 12 hours. My TB meningitis infection caused me to have seizures whenever I went into withdrawal, and the diarrhea and sweating that are part of detox were now much more dangerous to me as a person with advanced HIV-disease than they had been previously. For the first time in my life, I felt I had very little control over my ability to stop using heroin if I wanted to. Here's really where my ordeal begins.

After months of getting health care however and wherever I could, in the fall of 1996 I finally had health insurance and a doctor who agreed to work with me. This physician seemed truly intent on providing me with health care for my HIV-disease without unnecessarily problematizing my drug use. He made it clear that he felt it would be better if I wasn't using, but I didn't feel judged or belittled. After several weeks of seeing him, he offered me--without my asking--a Dolophine prescription that I found to be incredibly helpful as a drug management tool. He said it would always be available and all I needed to do was ask. (Since doctors can't prescribe methadone for maintenance, he prescribed it for "pain management.") I thought I had died and gone to heaven. For the next several months, having access to legal methadone without being on a clinic was extraordinarily helpful in letting me lead a stable life and still get high when I wanted or needed to. I could travel for work without having to make ridiculously complicated and risky arrangements, and my finances were more often in the black than the red. Unfortunately, my doctor came to believe that he was probably over-prescribing for me as far as the DEA was concerned, and since neither of us wanted him to get in trouble, I agreed to taper off the methadone when my doctor asked me to. What he hadn't told me, however, was that he'd already decided that the last prescription he'd written for me was the final one he would write. Because the rifampin ate away at the methadone I took, I found it impossible to successfully detox off this prescription, and wrongly assumed that he'd write me another until, within reason, of course, I could successfully detox. I felt extremely betrayed when, with absolutely no forewarning, I was told I couldn't get even one more script. I was out, and would have to find some dope that afternoon in order not to be sick. Although I understood and could sympathize with my doctor's very justified fears about the DEA, I couldn't get over the fact that he gave me no time to make some alternative plans. In what other circumstance would it be perfectly acceptable for a doctor to simply cut a patient off of medicine that was working perfectly?

My doctor was surprised and somewhat dismayed when I told him I'd rather shoot dope than go onto a methadone program.

My health problems were becoming increasingly severe. I was hospitalized twice in January 1997 for TB meningitis, and then twice more I would find myself admitted to--and checking out AMA from--the hospital. The 40 milligrams of methadone a day I was given was no match for the rifampin; after

the humiliation of begging for more methadone, I'd sometimes be given 40 more milligrams which, because by this time I'd been in complete withdrawal for several hours, had absolutely no effect on alleviating my withdrawal. Because I'd been given 80 milligrams of methadone--no matter that it was dispensed to me in a way that was completely ineffective--hospital staff and even my own doctor became annoyed when I complained that I was still in withdrawal. Drenched in sweat, wracked by stomach cramps and diarrhea, unable to eat or barely swallow my medications, and seizing like crazy, I was apparently supposed to be satisfied with the treatment I was receiving.

In both of these instances, I was in much worse shape *after* being in the hospital for two days than before I went in. Continual seizing made me confused for days, and caused me to have great difficulty speaking and thinking clearly. No amount of explaining to the doctors would convince them that the seizures I was having were being caused by the fact that they were forcing my body to go into withdrawal every several hours. In fact, on these two occasions my health was actually *jeopardized* because no one would or could properly medicate me. At one point there was talk about putting me in intensive care when a higher dose of methadone would have done the job. What was so wrong about providing me with proper opiate maintenance? I was again forced to be the non-compliant junky patient and, much to my doctor's chagrin, and with great difficulty on my part due to my weakened and traumatized body, checked out of the hospital AMA, vowing never to return unless I had within my *own* control the means to self-medicate my own body.

After these two traumatic hospital visits my heroin use admittedly was out of control and my depression was incredibly severe. Although I swore I'd never do it, at my doctor's urging but against all of my better instincts, I finally enrolled in a methadone program. The notion of surrendering my daily ability to function to a program where the staff made no bones about their opinion that I was a dysfunctional fuck-up was repugnant and utterly disempowering to me. It was unbelievably depressing to sit in waiting room after waiting room with a bunch of other junkies who thought they were being "saved"; I could only feel like a complete failure. I went armed with documentation from my doctor about the fact that I was taking rifampin and Dilantin and had next to no T-cells, but despite a showdown with the clinic doctor on my first day, I was told I'd be given only 40 milligrams of methadone and raised 10 milligrams a day until an "appropriate" dose was reached. (Apparently, I was lucky: most patients are started off at 30 milligrams and raised by increments of 5 milligrams a day.) Never mind that I had TB infection of the brain that caused me to seize when I experienced withdrawal and that I'd been shooting 10 bags of dope a day: I'd have to be content with 40 milligrams of methadone. Now in "drug treatment," I was nonetheless forced to continue to shoot dope on top of the methadone I was getting from the clinic or buying street methadone to supplement my dose. I soon had a double habit--dope and methadone--and found that several weeks later when I was finally receiving 90 milligrams of methadone at the clinic that even this dose, above which the clinic said it absolutely would not prescribe, was inadequate because of the effects of the rifampin.

I'd be at the clinic at 7:30 am sharp each morning, sick as a dog, to get my methadone. Because I was in withdrawal, it would take nearly an hour for the methadone to make me feel even slightly human. After spending the entire day feeling like I was constantly on the verge of withdrawal, I'd wake up each morning around 1:00 or 2:00 am, drenched in sweat and unable to sleep, again in complete withdrawal. I'd get up and, in intense pain, have to wait until 6:30 am to get dressed and travel half the length of Manhattan to the clinic, again drenched in sweat and freezing by the time I got there, to receive a non-therapeutic dose of methadone. I maintained this maddening schedule for nearly two

weeks, going into methadone withdrawal *every single day* --something that was physically very traumatic for my body and emotionally devastating--while trying not to supplement my dose so as to give the methadone a chance to work. The clinic continued to refuse to increase my dose, and every time I tried to explain to them that I was taking rifampin, the staff would look at me like I was simply trying to scam them for more methadone. What I actually needed--and what I am convinced anyone on rifampin and methadone needs--was not necessarily a higher dose of methadone but rather two doses of methadone a day. Even a regimen where I took half of the 90 milligrams in the morning and half later in the day would have worked better than what I was offered, but I was told that such an arrangement was impossible.

I was so physically and emotionally beaten down after several weeks of this routine, so tired of being sick every day, absolutely exhausted from a lack of sleep and the trauma of continuous withdrawal, and so infuriated that I'd humbled myself and asked for help only to be kicked in the teeth, that I was willing to do just about anything to get out of the cycle of daily withdrawal I was in that was so dangerous to my already debilitated body and quite literally driving me to suicide. Although I'd watched one of my former needle exchange clients die a gruesome death from tuberculosis, and although I'd been a health educator for years and knew very well the consequences of interrupting tuberculosis treatment, I stopped taking my daily rifampin dose in the hopes that my body would reach some point of homeostasis and the methadone would begin to work. (I was on three other TB medications, and hoped that if I became resistant to the rifampin the others would take up the slack.)

If my experience was at all typical, I am convinced that methadone programs--because of their unwillingness to properly medicate people taking rifampin for tuberculosis treatment--are responsible at least in part for the resurgence of drug-resistant and multi-drug-resistant TB New York City experienced in the 1980s and early 1990s. The program I was on at Beth Israel Medical Center in New York, in any case, was completely unwilling to accommodate even the serious, life-threatening health needs of the kind I was experiencing. Nothing, I was told, could be done about my dose or dosing schedule. Eventually I became too debilitated to travel to the clinic every day in order to receive my non-therapeutic dose of methadone. I ended up kicking the 90 milligrams I was on cold-turkey at home, a process that no doubt severely endangered my health and which caused me unbearable and completely unnecessary suffering, and a process which again landed me in the hospital for another two weeks because my body was so shot. In trying to make sense of my ordeal trying to access appropriate and humane health care, several themes come up again and again. Everywhere I went--from my private physician to the hospital to the methadone clinic--certain assumptions guided the care I received and what the providers would or would not do for me.

"Drugs are your real problem." Every provider I saw assumed that one of the most serious, if not the most serious, issue I was facing was my opiate dependency, despite the fact that this was not something I defined as problematic in-and-of-itself. (Of course, for harboring this attitude I was constantly accused of being "in denial.") Among the things that I was experiencing that I considered to be my most serious problems were: the TB meningitis infection I had and the seizures that it constantly caused; the fact that I had only 15 T-cells and a three-and-a-half million viral load, a condition that kept my body on the constant verge of collapse; the persistent, recurrent herpes zoster infection on my face and head, treatment for which entailed going to my doctor's office *every day*, including weekends, to receive an intravenous infusion of an extremely toxic drug; the fact that I was undoubtedly experiencing crazy drug interactions as a result of being on no fewer than 14 different

pharmaceuticals; the deep depression I was feeling as a result of trying to deal with such huge life changes by myself; and the challenge of trying to earn a living, pay the rent, and continue to perform my job successfully in the midst of this other shit. All of these issues would apparently resolve themselves if only I stopped shooting dope.

Like many other opiate-dependent individuals, I was fine when I was using. It was when I ran out of drugs that the difficulties began. Withdrawal was my real enemy during this whole ordeal and because of the effects of the rifampin, being under-medicated at the hospital and the methadone clinic, and being forced to switch back and forth between dope, street methadone, and the methadone I received through the clinic, I experienced more withdrawal while I was in "drug treatment" than I ever did while I was using. The constant withdrawal I was forced to undergo was so dangerous for my body and so hurtful to me psychologically, yet everywhere I went my use, and not the withdrawal, was perceived to be my problem.

"Opiates are ruining your health." There is a widespread belief among health care professionals that the "non-medical" use of opiates (at least heroin), apparently because it is illegal, is infinitely bad for the body. That was a risk I willing to take. In my estimation, however, the daily intravenous infusions of ganciclovir (Cytovene®) I was receiving for the treatment of herpes zoster were much more damaging to my body than the heroin I was shooting. One of the side effects of ganciclovir treatment is a severe depletion of the body's white blood cells (which to me doesn't seem like the greatest thing for a severely immunocompromised individual to undergo), and several times my white blood count reached such low levels that I had to be given Neupogen injections to stimulate their production. This artificial lowering and raising of my white blood cells can't have been very good for my body, but it was part of a medical treatment regimen and so apparently constituted an acceptable risk. I was also taking isoniazid (INH) for the treatment of tuberculosis, a drug which can cause iatrogenic hepatitis; Dilantin, which made my brain feel crazy all the time; and, as I mentioned, a host of other toxic pharmaceuticals that must have been causing drug interactions of all kinds. For a while I was taking the protease inhibitor nelfinavir (Viracept®), an extremely powerful substance that was tested in clinical trials of a mere several hundred individuals (none of whom were likely self-identified heroin or methadone users) for a period of less than a year. On the other hand, people have been shooting dope in the United States for more than a century now. I would not be surprised at all to learn that the Viracept and the two nucleoside analogues I was taking each day were much more dangerous to my health than the dope I was shooting. Certainly they were more toxic.

"Methadone programs are there to help you." My brief stint on methadone was one of the most humiliating experiences of my life. Everyone with whom I came into contact--from the intake counselors to the woman who drew my blood to the physicians' assistant who examined me to the dispensing nurse--treated me like shit *simply because they knew they could*. If I wanted to be medicated in a timely fashion or at all, I had to do exactly as they required, without protest or qualification. I could not get over the outright hostility with which even the most routine interaction with staff took place. Because they had control over you and knew it, no one hid the fact that they believed you to be completely dysfunctional, pathetic, and no doubt morally bankrupt. Knowing absolutely nothing about my life or circumstances, every staff member I dealt with harbored fucked-up assumptions about who I was and why I was at the clinic. At a time in my life when I needed some support, I was met with rejection, disgust, and hostility. The clinic's refusal to help me feel comfortable despite the fact that I was on rifampin was nothing short of criminal, and the role of

methadone clinics in the drug-resistant TB epidemic--if my case was at all typical--must be exposed.

I am completely on my own when it comes to my opiate use. I've always managed my habit on my own, problems and all, and enrolled in a methadone program (and gave up that control) only because my health problems were becoming so serious. I had to re-learn what I already knew very well: that I must remain in control of my ability to function, and never surrender this to any individual or agency ever again. My physician remains steadfastly unwilling to acknowledge that the extent to which I'm able to successfully and sanely manage my drug use has a direct impact upon my ability to manage my HIV-disease. He insists on treating only half of me--the part he feels comfortable dealing with--despite the fact that it is impossible to separate the issue of my opiate use from my overall health care needs. When I ask him why he refuses to write me a prescription for a few days' worth of Darvon or Dolophine to help me get through a detox, I receive a vague answer that he's "not comfortable" doing it.

It does bother me that I can't rely on my doctor to offer even moral support, and I have no idea if I had to go to the hospital tomorrow whether or not he would prescribe methadone for me during my stay. That I should be forced to purchase a supply of drugs or methadone to take with me to the hospital is insane, but I have no other choice. That I may have to put off checking into the hospital at some point in the future because I'm unable to get the money or the drugs together is criminal.

I'm sure there are people who'll read this and whose only response will be that I'm pretty fucking good at finding ways to rationalize my continued drug use. I have tried--and succeeded several times, for short periods--to stop using drugs during the past six months while I was experiencing the events I describe. Every time I encounter a health care professional, a social worker, or sometimes even a friend who counsels me to stop using, I listen and I struggle with what they have to say, yet I always ask, "Why? Why is it so crucial for me, someone with a life-threatening illness who finds in heroin terrific comfort and few adverse health effects (even health benefits) to stop using and subject myself to a disruptive, major life change?" I'm able to perform a challenging job successfully, have so far been able to continue paying the rent (albeit sometimes late), but most importantly, am willing to suffer the inconveniences and take the risks that are involved in using illicit drugs. That is a choice I'm willing to live with, and I'm so alone in believing that it is a choice that can be consistent with a happy and successful life. *That* is the hardest part about being a user: not internalizing the belief that I am a piece of shit and trying to live a life of satisfaction and dignity that everyone tells me is impossible

The author lives and works in New York City.

1. See American Thoracic Society, "Treatment of Tuberculosis and Tuberculosis Infection in Adults and Children" (a joint statement of the American Thoracic Society and the Centers for Disease Control, adopted March 1986). Reprints are available from your local Lung Association.



Research paper

Improving health and social care relationships for harm reduction

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Abstract

This paper explores elements of the relationships that develop between people who use illicit drugs and people who provide services to them. It focuses on expectations people who use drugs and service providers have of health and social care relationships for harm reduction, as well as facilitators and barriers to effective and ineffective interactions, and to what governments might better do to help strengthen interactions. Prior to Canada's inaugural national harm reduction conference, informal discussion groups were organized to source local views regarding policy reform for harm reduction. One component of these discussion groups focused upon improving health and social care relationships for harm reduction. Community-based organizations providing services for harm minimisation were consulted to help develop themes and questions. Discussion groups conducted in French or English were held in 10 cities across Canada. Groups were audio-recorded, transcribed and thematically analysed. Disjuncture between understandings of the nature of health and social care relationships for harm reduction were found. Interpersonal and structural factors functioned both for and against the development of effective interactions. Differences in expectation sets held by illicit drug users and service providers may reflect the fluid experience of boundaries as a population on society's margins moves between harm-causing and harm-reducing behaviours and identities. The research described in this paper targeted those most directly involved in receiving, developing and delivering harm reduction programmes across a very diverse nation. It did so by including representatives of those most directly involved in utilizing and providing services within the research process itself. By incorporating a process that was community-based, user-driven, and which strived to be non-judgmental, the research was able to explore suggestions for improving health and social care relationships for harm reduction proffered by professionals actively providing services, as well as a variety of users, including some isolated or structurally excluded from service access by geography, illiteracy and/or street-involvement.

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Keywords: Illicit drug use; Health and social care; Service relationships; Harm reduction; Focus groups; Participatory research; Canada**Introduction**

Targeted health and social care services for illicit drug users which include harm reduction is one of the benchmarks of a continuum of care within many health systems. As harm reduction services continue to develop, new and evolving understandings of the nature and extent of illicit drug use have called for modifications to service provision. One result is that some previously stigmatised and criminalised behaviours and lifestyles have been re-examined and re-considered. In many jurisdictions, both

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government policy makers and service providers have met evolving practice by fine-tuning harm minimising health and social care services to make them more cost effective and more responsive and meaningful to a range of different kinds of drug users. An ongoing goal is often to continue to improve services, and to ensure they meet the needs and requirements of consumers while being responsive to evolving client need and expectation (Laing, 2002).

Of those service providers who deliver health and social care to people who use drugs, some appear to have been more effective than others in affecting such shifts. Many community pharmacists, for example, have successfully introduced ground rules for the services they provide, as have some clinic-based counsellors (Myers, Cockerill, Worthington, Millson, & Rankin, 1998; Matheson, Bond, & Pitcairn, 2002). Less has been documented of the expectations and experiences of street-based and other service providers and the health and social care relationships they develop with illicit drug users. Although there is considerable public and academic debate over the success, efficacy and ultimate value of services for harm minimisation (McKeganey, Morris, Neale, & Robertson, 2004; Reuter & Pollack, 2006) – both in terms of its outcome and its cost – there is some consensus within the literature that making harm reduction services available for a variety of drug dependencies is desirable both for the reduction of drug-related harm as well as drug dependence cessation (McLellan et al., 1996; Hser, Anglin, Grella, Longshore, & Prendergast, 1997; Prendergast & Podus, 2000). Provision, to quote Reuter and Pollack “can justify itself in terms of reductions in harms to individuals and communities” (2006:341). Not only can sensitively delivered services help to reduce the harm associated with an individual’s drug use, they can lead also to broader improvements in health and employment outcomes and reduction in the risk of other harms, like crime and related violence (Grosenick & Hatmaker, 2000). Often, however, minimising harms associated with illicit drug use may necessitate some shift in the ways providers and others envision and understand the use and needs of people and subcultures who either exist below society’s radar or function at its edge. For drug users, as for other marginal groups, the migration between harm-causing and harm-reducing behaviours can require some movement between one social order and identity to another (Park, 1928).

This paper examines experiences within health and social care services as one element of the harm reduction continuum. It explores how a sample of illicit drug users and those who provide services to them experience care, and some of the expectations users and providers have of these working relationships. It examines some similarities in terms of the experiences of these two groups of stakeholders as well as where sets of expectations and experiences may differ. It explores also the kinds of beliefs participants voiced about how governments in general could

help improve health and social care relationships for harm reduction.

In November 2002, Canada held its first nation-wide harm reduction conference in Toronto. This was a gathering of current and former drug users, peer educators and front-line workers to respond to critical and emerging issues through three primary streams: skills building and education, policy development and networking. Within the context of the conference, harm reduction was defined as: “a practical approach to drug use. It recognizes that quitting drugs may not be realistic or desirable for everyone.” (Ages, Allman, & Cowan, 2003).

The event was a long time in the making. As early as 1997, a Canadian national task force on HIV/AIDS and injection drug use had stated that the country was in the midst of a public health crisis concerning HIV and injection drug use, as the virus was continuing to spread in vulnerable populations with little regard for geographical boundaries (Canadian Centre on Substance Abuse and Canadian Public Health Association, 2001). One response to this crisis was envisioned as a national meeting where harm reduction proponents could share harm minimising strategies, education methods and networking skills. As evidence-based decision making has a demonstrated track record as a basis for substance abuse and harm reduction policy (United Nations Office for Drug Control and Crime Prevention, 2002), the funding body and the conference organizers preceded the conference with a community-based national pre-conference needs assessment. Research was to become central component of the conference, in part, because community and governmental stakeholders hoped it could be a mechanism to bring local views forward prior to the event to inform the conference organization and programme, and to help orient discussions on policy reform for harm reduction in Canada (Allman, 2002). Within this context, the research activity functioned as a mechanism to allow conference organizers to understand the full range of potential supports and services required to help guarantee the safety and well-being of attendees – the majority of whom would be illicit drug users or service providers.

Method

Early in the planning stages of the first Canadian national harm reduction conference, current or former illicit drug users with ties to their communities were recruited from across the country to act as peer networkers. Existing communication networks were built upon to recruit 15 individuals. These networkers were frequently the research teams’ point of community contact, undertaking local coordination, promoting research data collection and providing feedback on data collection instruments. Researchers sought to recruit as broad a sample as possible for discussion groups through advertising, the internet and word-of-mouth. Discussion groups were conducted in five regions. Discussion groups were

equally divided between larger metropolises and smaller cities and remote or rural towns. Groups were organized by peer networkers and host agencies and conducted by researchers. Each participant was offered a small honorarium to cover costs associated with attending. Groups lasted approximately 90 minutes, and were conducted in French or English. A discussion guide was developed in consultation with peer networkers and research advisors. Groups were audio-recorded, transcribed and thematically analysed (Babbie, 1999). Data coding was structured on qualitative data handling practice following Ritchie & Lewis (2003). This included initial coding to identify themes, the addition of a second coding layer to identify broader social concepts, and the utilization of a third analytic layer to move from initial concept identification to explanation. Techniques for analysis were further influenced by the grounded theory of Strauss (1987), and the open coding of Strauss & Corbin (1990).

All participants provided informed consent to participate in the research and to have the results disseminated in a variety of ways. The provision of informed consent was an active process achieved by discussing the research and consent process with participants in order to ensure that all understood participation was wholly confidential. To ensure this, no demographic information was collected nor were specifics of actual drugs used or services accessed explored. Further, all dissemination of these research activities avoided attribution to any one data collection region. In order to assist the analysis presented here, names to which quotes are attributed are generated by a random, gender neutral name generator.

The objectives of the discussion groups were to discuss the upcoming conference; to reflect upon local and national networking for drug users and service providers; and to consider the nature of effective health and social care relationships. This paper focuses on the latter objective. To explore this topic, three broad questions were discussed: (i) what makes for good working relationships between people who use drugs and service providers; (ii) what can damage these relationships; and (iii) what could governments do to strengthen these relationships?

Results

In total, 20 discussion groups were held, 10 for current illicit drug users and 10 for service providers and previous illicit drug users. Seventy-four individuals participated in discussion groups for drug users and 60 in groups for service providers and previous users. Attendance ranged from three to 10 individuals. Groups were held in three large metropolitan cities of between one and four two million residents, three mid-size cities of between 200,000 and 900,000 residents, and three small, remote cities of between 25,000 and 75,000 residents. Sixteen discussion groups were conducted in English and four in French.

Characteristics of effective relationships

Similar characteristics described by both illicit drug users and service providers

In general, discussions revealed many common experiences and expectations of effective health or social care relationship relationships, and factors that helped facilitate their developments. "Attentive" interaction, that is, the utility of service providers to actively and attentively listen and respond to information shared within health and social care relationships was seen as beneficial. A second valued characteristic commonly described was "direct" interaction, that is, service providers who could be "straight up" or direct within a health and social care interaction. "Confidentiality" was described as an important characteristic, as actors entered service situations with the expectation and hope that service providers would maintain and not disclose information provided. The maintenance of confidentiality was seen as primary and essential to developing "trust," as was the service provider who was "patient." Discussants frequently described the advantages of service provision that demonstrated patience across various stages of health and social care interactions, particularly for clients who either had ceased to consume illicit drugs or had reduced harms associated with such use and subsequently relapsed. The wish for "respectful" service provision and "supportive" interaction, regardless of whether the provider might express personal feelings (sympathy or empathy) concerning a client's circumstances, lifestyle choices or drug use was frequently described. "Non judgmental" service provision was a further characteristic described as beneficial, that is health and social care services that did not pass judgment on substance use, lifestyle choices, or individual or group characteristics.

The most frequently discussed effective component of health and social care relationships would describe a provider as "experiential", that is a service provider who "had been there; done that," who had personal experience with drug use. This referred particularly to those who may have successfully managed to migrate from harm-causing to harm-reducing or abstaining activities. Experience was seen as a most important element of these interactions as it allowed service providers to understand where people "were really at." Being experiential most often meant the service provider had a history of drug use, and had subsequently moved beyond their drug use. Those who had been there and had exited successfully were viewed as particularly able to understand the realities of a life that included illicit drugs, as well as the challenges faced by those attempting to cease or reduce drug-related harm. The very existence of such service providers was contextualised "as an example and an inspiration."

Variation in descriptions of effective service relationships

Beyond the common characteristics most discussants agreed were instrumental in forging effective health and

social care relationships were a series of diverging characteristics which different sets of participants used to describe effective service relationships for drug-related harm reduction. For illicit drug users, these included service providers who were "experienced" in service provision for harm reduction (as opposed to experiential); who were "known" and "reputable" within drug-using networks and who could be counted on to be "there to listen." Service providers were favoured if they were "approachable," "caring," "sensitive," "empathetic," "understanding," "helpful," "honest," "open-minded" and able "to make a person feel at ease." Participants who used drugs also expressed the benefit of service providers who were "communicative" and presented an "upbeat" attitude; who were neither "patronizing" nor "prejudicial," and who entered the service relationship with "no perceived expectations."

Participants within service provision discussion groups tended to envision effective relationships somewhat differently. Within these groups, service provision interactions were seen as beneficial if the person delivering services was "ethical" within their interactions with clients and able to "focus on the client rather than their drug use." A good service provider was considered one who was "firm" and able to foster "open dialogue" using "common language" and demonstrating "explicit boundaries." Effective service provision was possible if the person delivering the services was "self-reflective" and "authentic." That person needed to be "accepting" and to manifest an "ability to bond;" to be "welcoming," "friendly" and "demonstrative," to value people "unconditionally" and to be "accessible" and "available."

Thematic groupings of descriptions

Characteristics described by both categories of participants were able to be grouped into three broad themes, defined here as (i) professional (reflecting a courteous, conscientious, and generally businesslike workplace manner); (ii) affective (relating to, arising from or influencing feelings or emotions); and (iii) affirmative (favouring or supporting a chosen course of action). Whereas agreement between service providers and drug users tended to reflect upon effective professional characteristics, there was less agreement on the affective and affirmative characteristics of good health and social care relationships. Illicit drug users tended to favour affective interaction while service providers tended to favour affirmative interactions. In general, when described by discussion groups for illicit drug users, characteristics of good service provision interaction reflected greater attachment to personal and interpersonal elements, whereas those described by service providers tended to reflect a greater reserve and caution – perhaps an indication of the realities of the work, the incidence of relapse or return to drug use on the part of those abstaining from drug use, and the high rates of burnout among agency co-workers and others. Of note is the belief that the success and efficacy of harm reduction relationships rested almost exclusively on the shoulders of service providers.

Despite probing by facilitators, neither drug users nor service providers focused to any extent on the responsibilities consumers brought to the health and social care interaction, or traits that made a client an effective participant in a care relationship.

What can damage these relationships?

The second structured question within discussion groups focused on what could damage service provision relationships. For drug users, the breaking of trust was a major issue. Service providers who were "suspicious;" who believed "all needs are motivated by drugs;" or who were "unable to see beyond the drug use" were seen as less capable of effectively delivering harm reduction. A lack of "professionalism," and respect and not recognizing free will and choice were cited as damaging as well. Users stressed that relationships were easily hurt by service providers who attempted to "force their answers or solutions on you," or by health and social care situations where "things are enforced on you." Users also identified a tendency for health and social care services in general, and relationships between users and providers in particular, to lack an ability to embrace other, more mainstream approaches to well-being, such as the overall physical and mental health of an individual, and not their drug-use issues alone.

As with users, service providers also identified breaches in trust and confidentiality as actions that could damage service relationships. Providers who were overly curious, gossipy, insincere or voyeuristic could lose the confidence of the client. Unreasonable expectations also could damage, such as: "expectations that people won't fuck up and won't relapse," or seeing "clients as an extension of themselves and their successes." For service providers, the manner in which they comported themselves and behaved was a recurrent theme. Burnout, restrained body language, and even being overly professional could all have detrimental effects. Environmental factors, such as "busy days like methadone days when one is essentially doing crowd control," and the difficulties some service consumers had "keeping appointments and being on time" could be counterproductive as well.

What governments could do to strengthen relationships

Participants were asked to reflect upon what governments in general (federal, provincial and local) could do to strengthen relationships between people who use drugs and people who provide services. Consistently this was the theme which elicited the most passionate and articulate response. Indeed, it seemed to be a topic that was frequently discussed within participants' professional and social networks. Whereas discussion groups with drug users tended to focus

on government action more broadly, service providers were more direct and critical in their response.

Views of illicit drug users

Drug users stressed that governments could take a more active role improving the relationships between drug users and service providers. A common sentiment was that policy and policy makers were simply too far removed from the realities of health and social care service provision:

Government should come out and see what day to day existence is like. (Phoenix)

The government [should] experience what we do, not read statistics in a report. (Kendall)

Many drug users also felt that care relationships could be improved if governments made more services available, therefore allowing service providers more tools with which to help users:

More detox. (Shannon)

Latitude and more authority for service providers to do more for addicts. (Taylor)

Allow more alternative medicines for these services that can actually go in and get to the heart of the matter. We need to legitimize and pay for these medical services. (Jay)

Public education

Discussion groups with drug users spoke to a need to educate the public, not only about drugs, but also about life skills that could be used to help refrain from drug use:

At 18 they kicked me out of my foster home they didn't show me no life skills, they didn't teach me how to fend for myself or nothing. When I got out they said there is the street, fend for yourself. There has got to be stuff [to learn]. Life skills . . . what you learn is survival skills, how to survive on the streets. (Rylee)

I think the Department of Health and the Department of Education have to get together . . . to work with experiential learning . . . they need to teach people who are learning to be teachers, life skills. It should be mandatory and they need to teach life skills in school so that when these kids get out on their own at 14 or 16 they at least know how to make friends and how to choose friends and how to hang on to them and what a commitment is and what responsibility is and I think there is your answer right there. The people who are teaching children have to learn and then they have to teach it in school. Being an addict I am on the outside I feel. I would like to reach people that aren't addicted and

don't have problems and educate them that we are human beings; we are part of society too, but I have always felt outside and not able to talk to straight people. I would like to see more of that, more across-the-board education. (Carson)

Education was a recurrent theme, and drug users frequently discussed the need to educate – and in some cases re-educate or re-train service providers in order to allow for more effective interpersonal interaction:

Have more training for the service providers so that they can bring this to their communities. (Dylan)

Retraining for service providers and special parts of a student's practicum that deal directly with harm reduction. (Tyler)

Views of service providers

In contrast to the suggestions for government policy and action suggested by users, service providers tended to focus more specifically on structural issues, such as education and training, the workplace, government bureaucracy and funding. Providers concurred that a lack of suitable education and training was a deficit. Many recognized service provision within the field of harm minimisation was an evolving expertise, and that the skills required to effectively do the job would require replenishing as a matter of course:

Educate service providers so that they remain progressive in the field. (Ali)

Sponsor a trainer program where one person in a region goes and learns skills and then returns to share them with their peers. (Parker)

Service providers also discussed best practices, and the difficulty identifying, and by extension, utilizing, the most up-to-date information.

I would like to see a best practices document on harm reduction. (Alex)

[The government] might be able to . . . through a best practices document . . . to encourage the provinces or the health agencies within the provinces to work in a more integrated way. (Drew)

Workplace issues

Workplace issues were frequently discussed. These took the form of suggestions for action to improve workplace environments, thus enabling the development of more effective relationships between provider and consumer. These included job security as well as the physical, emotional and

legal safety of individuals who choose to work within the field.

Where is the safety, where is the safety network for people on the front lines? Where I am working we are trying to find that safety network. We are all long-term offenders who have been released working with long-term offenders inside and outside and sometimes you can be in a situation where one of your clients . . . gets busted in your company and you get busted too, you lose your job and get sent back to prison because of the job you are doing and this is something that has happened to people across Canada in the job that I do and this is something the government is going to have to look at. (Reagan)

The respect they give our type of work? Oh, you are a street worker? Are you a social worker? Oh, no, no you're not a social worker. Its like: what education do you need to do that? Oh, you don't need any studies particularly. You know, we hear these kinds of things all the time. We are frontline with these users. I'm not saying we know everything but we have particular knowledge that [governments] certainly are not getting in their offices . . . It is a respect of this kind of work: a recognition of the necessity and importance of frontline work. (Pat)

For many providers, working with drug users was experienced as a demanding job. Many felt governments could do more to support people in the workplace, particularly as the work could be emotionally and psychologically demanding, and could often lead to burnout:

Workloads are too large. (Morgan)

Support for the service provider for whom this work can raise personal issues. (Bev)

Governmental bureaucracy

Service providers also suggested government bureaucracy had a role to play in improving care relationships between users and providers. For example, the large amounts of paperwork required to remain accountable, such as a need for receipts, demands for case management documentation, and the need to constantly re-apply for project funding, could prevent workers from fully focusing on the needs of consumers.

They are always asking for new projects when we know that the old ones are good. (Jamie)

A repeated concern was that governments did not always appreciate the sensitive quality of information service providers were privy to through their interactions with clients. Service providers believed their ability to keep information confidential was integral to the development of trusting harm-reducing relationships, but that often it was precisely this

confidential information which governments required them to report.

Respect confidentiality between service provider and client. (Chase)

Not expect or require sensitive information to be shared. (Alex)

There is a contradiction with Revenue Canada because if we pay peers, we have to provide them with a [tax income statement] and if we issue a [tax income statement] then if they are on disability or are a user . . . it discloses their drug history and it can mess up with their disability. (Dana)

Funding structures

A final theme identified by service providers concerned funding. It was strongly believed that a workplace able to provide more secure and longer-term funding would translate to more effective health and social care relationships for harm reduction. Stable funding was seen as instrumental in reducing staff turnover while facilitating a more consistent focus on client need.

Even long term agencies have to spend every year looking for more funding. (Harley)

Something that the government could do that would make our jobs easier, I think it somehow all relates to long-term, long-standing funding for community-based organizations . . . because we are poorly paid; poorly supported. (Reese)

Counsellor salaries are all short-term contracts. How can these relationships develop without secure funding and long-term counsellors? (Sage)

Discussion

Grosenick & Hatmaker (2000) suggest that for improved human service delivery, investigating the desired characteristics of service providers and other staff is extremely relevant as it is this human capital which ultimately controls the service encounter, and it is the management of this control coupled with clients' perception of this power which are instrumental in creating a context for effective substance abuse treatment. The kinds of characteristics frequently discussed in the literature as helping to ensure quality health and social care interactions include communication, hospitality, courtesy, friendliness, enthusiasm, respect and 'simple nice-ness' (Scully, 1995; Preston, 1997; Zenger, 1997; Grosenick & Hatmaker, 2000). In turn, service providers and staff have been found to garner respect if they are perceived as humanistic, caring, and sensitive, while at the same time exhibiting the determination that they will and can 'get tough' if required

(Grosenick & Hatmaker, 2000). Clearly, attitudes and motivations illicit drug users hold towards accessing harm reduction services will vary, as will expectations for what these services will or will not be able to offer and provide (Zweben, 2002). Individuals motivated to reduce drug use or to minimise harms associated with use have been found more likely to report care services to be useful. Conversely, those with less motivation have been found to be less favourably oriented or satisfied with available services (Woff, Toumbourou, Herlihy, Hamilton, & Wales, 1996). Logic suggests—and research supports this—that given the choice, illicit drug users prefer to access services that best meet their needs and best respond to their expectations. Furthermore, illicit drug users will tend to avoid—if at all possible—services that are disrespectful, judgemental, negative, hostile, stereotypical or biased against providing that which is actually sought (Reid & Klee, 1999; McLaughlin, McKenna, & Leslie, 2000). Indeed Grosenick & Hatmaker (2000) found four factors seemed to determine the overall success of harm minimisation treatment: staff knowledge and experience, supportiveness, nonthreatening behaviours, and availability. Adams & Drake (2006) found that interactive, shared decision-making provides, not only to the development of information and an understanding of choices available, but can create the context within which client needs and preferences can be heard and responded to. For these reasons, simply making systems for harm minimisation available in a community may not be sufficient without a concentrated attempt to link the characteristics of the harm reduction services provided with the expectations of the drug users who access them. This is because the services targeted at people who use illicit drugs, prejudicial attitudes really can prevent people from accessing effective and humane health and social care, including care that falls within the range of services described as harm-reducing (McLaughlin & Long, 1996). Thus, rational approaches for matching patient expectations with services provision are required (Widman, Platt, Lidz, Mathis, & Metzger, 1997). As Bonner (2003) explains, social programmes and projects intervene not only within intervention contexts, they also have some ability to alter the social capital of people and communities, and help them reason and make choices. However, it is not programmes alone that lead people to change or minimise harm-causing behaviour. Rather, it is frequently programmes in tandem with individual service providers that do so. It is individuals who have some of the greatest potential to generate change in specific contexts through interactions built upon their powers and capacities, and use thereof.

Occupational safety; an ability to meet the expectations of clients through better caseload management and more stable working environments (Myers et al., 1998; Thompson et al., 1998)—these are as essential for services to be useful for drug users, as is recognition of changing demands and expectations placed on providers in a context where the availability of illicit drugs may be erratic, where drugs of choice often evolve, and where increasingly educated individuals, with a greater diversity of service needs, seek new

and novel ways to reduce the harms associated with drug use (Hartnoll, 1992; Zweben, 2002). For these reasons, the boundaries framing harm minimising relationships are often aided by the incorporation of some flexibility, as flexibility can allow a service provider to meet diverse client need and respond to unexpected situations (Strike, O'Grady, Myers, & Millson, 2004). At the same time, flexible boundaries can lead to blurred boundaries, and hence, may contribute to varying and fluid expectations. As Strike et al. (2004) found, limiting roles at the same time as delivering services can lead to environments in which the boundaries of roles become overly ambiguous and potentially problematic.

Anderson & Levy (2003) apply Robert Park's (1928) concept of the 'marginal man' (or marginal person) to the realm of illicit drug use. That is, any drug-using individual, who, at an intermediate point between two distinct cultures, may embody contradictory normative expectations, behaviours and beliefs. Just as the older users considered in the work of Anderson and Levy were seen to move from central to marginal positioning within an illicit drug culture, so too may individuals migrate from self-identities of more harmful drug use to self-identities more amenable to help-seeking and harm minimisation. Improving service provision may require shifting understandings of the potential challenges resulting from such migration. Models of service provision within these contexts may need to pay greater attention to the potential fluidity of social and cultural boundaries experienced as marginal men and women move between harm-causing and harm-reducing behaviours.

It has been suggested that the provision of harm-reducing and minimising services be monitored and evaluated in the same way that the provision of similar services are when provided to less marginalised client groups (Neale, 1998). Clearly the need exists for managed and continuing research on users' views of service providers as well as service providers' views on users. Equally clear is the fact that illicit drug users alone cannot "provide the definitive statement about the value of drug service provision." any more than service providers alone can. McLaughlin et al. (2000) found deficits in the knowledge, skills and values of health care professionals in relation to illicit drug users, indicating, that the kinds of knowledge and the attitudes and expectations held by service providers do play a fundamental role in the experiences drug users have with the services they access: Neale (1998) suggests that drug users will often be at the frontline of service evaluation, and many will know that a good service provider will be knowledgeable about drugs and their use, and will have a non-judgemental, non-stigmatising attitude to drug users.

McKeganey et al. (2004) indicate that generally speaking, within health and social care settings, the consumer perspective has become embedded in virtually every aspect. Yet, within services targeted toward drug users, consumerism or the client-centred approach is perhaps not as fully integrated (Neale, 1998; McKeganey et al., 2004). It may come down to a particular form of client-centred mutu-

ality that favours—not so much a practitioner dominance where providers unilaterally make all decisions—but rather a more balanced approach where decision-making is shared between practitioner and client. The benefits of the latter approach can be argued from theoretical, ethical, economic, epidemiological, and clinical perspectives. (Adams & Drake, 2006).

Findings from 20 discussion groups held with current and former drug users and service providers revealed some common beliefs, experiences and expectations as to the nature of effective health or social care relationship relationships, and how these might be improved. Notable were the ways in which idealised characteristics diverged, along professional, affective and affirmative dimensions. Breaches of trust, a lack of professionalism, and an inability to recognize free choice were seen as particularly damaging. Service providers reported providing health and social care to drug users was often a complex and exhausting activity, with burnout being a common result. The most animated reflections in all discussion groups were reserved for reflections on what governments could do to strengthen relationships between people who use drugs and people who provide services to them. Here, respondents favoured a more active role on the part of governments and policy makers, as this would potentially lead to more and improved services becoming available. The need to educate the public, broadly and realistically about drug use and its prevention was a recurring theme among participants, while models of best practice and other workplace issues including bureaucratic reporting requirements and a lack of occupational security were seen by service providers as limiting the effective delivery of services.

This paper reflects upon a range of observations from illicit drug users and service providers of the situation with respect to the provision of harm reduction services in Canada. However, it does so within the context of several limitations. First, the division of the nation into five pre-determined regions coupled with research budget limitations did not allow an exhaustive reflection of the breadth of views nationally. Second, the nature of the convenience sample and limitations in recruitment may have functioned to inaccurately reflect the full range of realities or opinions. Third, national findings relating to Canada, with its unique proximity to the United States of America's drug wars, may have limited application with regards to other countries and contexts.

This research has led to some reflections on the training received by health and social care service providers working within harm reduction today, and this leads to the question of whether enough is being done to train service professionals to competently function within harm reduction frameworks. In a Scottish sample of service providers, while more than three-quarters had received national clinical guidelines pertaining to drug dependency, less than one-quarter believed these guidelines had influenced their practice. Further, only one-third had received any training regardless of a relatively high involvement with drug users (Matheson, Pitcairn, Bond, van Teijlingen, & Ryan, 2003). The evidence suggests that

a compendium of best practices alone may not suffice, and that other forms of training, capacity and skills building for the provision of harm reduction services may be required. Beyond training issues, this research reflects also an ominous sense of structural and material precariousness within which service professionals provide harm reduction to illicit drug users in Canada. It is among the most disturbing findings of this investigation. Previous research has reported that scarcity of resources within a service setting, and barriers to accessing such resources, can lead to conflicts in expectations between health service users and providers (Bronfman, Castro, Zuniga, Miranda, & Oviedo, 1997a, 1997b). This is one of the recurrent themes that might most warrant future investigation.

Today, many countries experience environments where negative community concerns about needle exchanges, methadone programmes and other drug services help to foster climates antithetical to the provision of harm-reducing activities (Allman, 2005). The irony is that this is occurring at a time when communities, service providers, researchers, and grass-roots policy makers are beginning to truly understand the makings of truly effective harm minimisation (Canadian HIV/AIDS Legal Network, 1999; Health Canada, 2001; Kerr, Douglas, Peeace, Pierre, & Wood, 2001; Ogborne, Carter, & Wiebe, 2001; Allman et al., 2006). Within such an environment the first Canadian Harm Reduction Conference developed a civil society-oriented approach to tackling these issues by allowing members of a marginal and traditionally excluded subculture to dialogue with both those providing and allocating services, as well as those forming and setting policies that underpin service availability. The accompanying research activities described here targeted as well, those most directly involved in receiving, developing and delivering harm reduction strategies across a very diverse country, and it did so by including representatives of those most directly involved in utilizing or providing these services. By incorporating a response that was community-based, user-driven, and which strived to be non-judgmental, these research activities pursued a greater understanding of what might be required to improve health and social care relationships for harm reduction. It did this by seeking out the suggestions of professionals actively providing services, as well as illicit drug users, including some isolated or structurally excluded from access to services by geography, illiteracy, and street-involvement.

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Advice from an ER doctor to drug seekers

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OK, I am not going to lecture you about the dangers of narcotic pain medicines. We both know how addictive they are: you because you know how it feels when you don't have your vicodin, me because I've seen many many many people just like you. However, there are a few things I can tell you that would make us both much happier. By following a few simple rules our little clinical transaction can go more smoothly and we'll both be happier because you get out of the ER quicker.

The first rule is be nice to the nurses. They are underpaid, overworked, and have a lot more influence over your stay in the ER than you think. When you are tempted to treat them like shit because they are not the ones who write the rx, remember: I might write for you to get a shot of 2mg of dilaudid, but your behavior toward the nurses determines what percent of that dilaudid is squirted onto the floor before you get your shot.

The second rule is pick a simple, non-dangerous, (non-verifiable) painful condition which doesn't require me to do a four thousand dollar work-up in order to get you out of the ER. If you tell me that you headache started suddenly and is the 'worst headache of your life' you will either end up with a spinal tap or signing out against medical advice without an rx for pain medicine. The parts of the story that you think make you sound pitiful and worthy of extra narcotics make me worry that you have a bleeding aneurysm. And while I am 99% sure its not, I'm not willing to lay my license and my families future on the line for your ass. I also don't want to miss the poor bastard who really has a bleed, so everyone with that history gets a needle in the back. Just stick to a history of your 'typical pain that is totally the same as I usually get' and we will both be much happier.

The third rule (related to #2) is never rate your pain a 10/10. 10/10 means the worst pain you could possibly imagine. I've seen people in a 10/10 pain and you sitting there playing tetris on your cell phone are not in 10/10 pain. 10/10 pain is an open fracture dangling in the wind, a 50% body surface deep partial thickness burn, or the pain of a real cerebral aneurysm. Even when I passed a kidney stone, the worst pain I had was probably a 7. And that was when I was projectile vomiting and crying for my mother. So stick with a nice 7 or even an 8. That means to me you are hurting by you might not be lying. (See below.)

The fourth rule is never ever ever lie to me about who you are or your history. If you come to the ER and give us a fake name so we can't get your old records I will assume you are a worse douchetard than you really are. More importantly though it will really really piss me the fuck off. Pissing off the guy who writes the rx you want does not work to your advantage.

The fifth rule is don't assume I am an idiot. I went to medical school. That is certainly no guarantee that I am a rocket scientist I know (hell, I went to school with a few people who were a couple of french fries short of a happy meal.) However, I also got an ER residency spot which means I was in the top quarter or so of my class. This means it is a fair guess I am a reasonably smart guy. So if I read your triage note and 1) you list allergies to every non-narcotic pain medicine ever made, 2) you have a history of migraines, fibromyalgia, and lumbar disk disease, and 3) your doctor is on vacation, only has clinic on alternate Tuesdays, or is dead, I am smart enough to read that as: you are scamming for some vicodin. That in and of itself won't necessarily

mean you don't get any pain medicine. Hell, the fucktards who list and allergy to tylenol but who can take vicodin (which contains tylenol) are at least good for a few laughs at the nurses station. However, if you give that history everyone in the ER from me to the guy who mops the floor will know you are a lying douchetard who is scamming for vicodin. (See rule # 4 about lying.)

The sixth and final rule is wait your fucking turn. If the nurse triages you to the waiting room but brings patients who arrived after you back to be treated first, that is because this is an EMERGENCY room and they are sicker than you are. You getting a fix of vicodin is not more important than the 6 year old with a severe asthma attack. Telling the nurse at triage that now your migraine is giving you chest pain since you have been sitting a half hour in the waiting area to try to force her into taking you back sooner is a recipe for making all of us hate you. Even if you end up coming back immediately, I will make it my mission that night to torment you. You will not get the pain medicine you want under any circumstances. And I firmly believe that if you manipulate your way to the back and make a 19 year old young woman with an ectopic pregnancy that might kill her in a few hours wait even a moment longer to be seen, I should be able to piss in a glass and make you drink it before you leave the ER.

So if you keep these few simple rules in mind, our interaction will go much more smoothly. I don't really give a shit if I give 20 vicodins to a drug-seeker. Before I was burnt out in the ER I was a hippy and I would honestly rather give that to ten of you guys than make one person in real pain (unrelated to withdrawal) suffer. However, if you insist on waving a florescent orange flag that says 'I am a drug seeker' and pissing me and the nurses off with your behavior, I am less likely to give you that rx. You don't want that. I don't want that. So lets keep this simple, easy, and we'll all be much happier.

Sincerely,
Your friendly neighborhood ER doctor

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Mutual Mistrust in the Medical Care of Drug Users

The Keys to the "Narc" Cabinet

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OBJECTIVE: Caring for patients who are active drug users is challenging. To better understand the often difficult relationships between illicit drug-using patients and their physicians, we sought to identify major issues that emerge during their interactions in a teaching hospital.

DESIGN: Exploratory qualitative analysis of data from direct observation of patient care interactions and interviews with drug-using patients and their physicians.

SETTING: The inpatient internal medicine service of an urban public teaching hospital.

PARTICIPANTS: Nineteen patients with recent active drug use, primarily opiate use, and their 8 physician teams.

RESULTS: Four major themes emerged. First, physicians feared being deceived by drug-using patients. In particular, they questioned whether patients' requests for opiates to treat pain or withdrawal might result from addictive behavior rather than from "medically indicated" need. Second, they lacked a standard approach to commonly encountered clinical issues, especially the assessment and treatment of pain and opiate withdrawal. Because patients' subjective report of symptoms is suspect, physicians struggled to find criteria for appropriate opiate prescription. Third, physicians avoided engaging patients regarding key complaints, and expressed discomfort and uncertainty in their approach to these patients. Fourth, drug-using patients were sensitive to the possibility of poor medical care, often interpreting physician inconsistency or hospital inefficiency as signs of intentional mistreatment.

CONCLUSION: Physicians and drug-using patients in the teaching hospital setting display mutual mistrust, especially concerning opiate prescription. Physicians' fear of deception, inconsistency and avoidance interacts with patients' concern that they are mistreated and stigmatized. Medical education should focus greater attention on addiction medicine and pain management.

KEY WORDS: injection drug use; physician-patient relations; attitude of health personnel; trust; pain treatment; ethnography.

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There is a great deal of antagonism set up, because the doctors are the ones with the keys to the "narc" cabinet... and the patients are the ones who need and want the narcotics, both for real and objectifiable and unobjectifiable reasons, and that puts all the doctors in a difficult position.—Senior Medical Resident

When patients who are actively using illicit drugs are admitted to the hospital, physicians in teaching hospitals confront some of their most challenging work.¹ Addressing the dangers of an acute illness while giving appropriate consideration to the addiction that has often led to hospitalization can be complex. Patients may not be ready for addiction treatment, and even if they are, access to such treatment is limited.^{2,3} Acute and chronic psychosocial issues can manifest as behavioral problems¹ that, coupled with the stresses of medical training, may be frustrating for physicians and staff.

Historically, physicians have been excluded from a major role in the treatment of opiate addiction.⁴⁻⁶ The Harrison Act of 1914 and the subsequent prosecution of physicians who maintained opiate addicts in a medical setting provided stark incentives to avoid treating addiction problems.⁵⁻⁸ Under current law, physicians may treat opiate withdrawal symptoms in addicted patients who are hospitalized for medical conditions other than addiction. Further addiction treatment, including methadone maintenance, is strictly regulated, requiring special state and federal registration.⁹ This isolation of addiction treatment has contributed to the well-recognized lack of physician skills in the screening, assessment, treatment, and referral of patients with substance abuse problems.¹⁰⁻¹²

Interest in expanding physician involvement in assessing and treating substance use disorders has been sparked by the recognition that these disorders are associated with a major proportion of preventable deaths.^{13,14} Patient outcomes have been improved after brief physician interventions to help patients quit smoking¹⁵ and decrease problem drinking.¹⁶⁻¹⁸ The integration of opiate addiction treatment with methadone into medical practice has been the focus of several successful trials and is becoming recognized as a legitimate treatment for successfully stabilized patients.¹⁹⁻²³ New addiction treatment medications are likely to give further momentum to this integration in the future.^{2,24,25}

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In spite of these advances, little empirical data has informed the physician's role in opiate addiction management in the teaching hospital. To develop preliminary data and describe existing patterns of care and tension in this demanding arena, we investigated the experiences of drug-using patients and their physician teams as they interacted over the course of inpatient treatment in a public teaching hospital.

METHODS

Design

We chose focused ethnography^{26,27} as our research method, a qualitative approach especially useful for generating initial themes and hypotheses concerning a relatively unexplored social setting. Researchers use empirical means such as direct observation or in-depth interviews in order to arrive at an understanding of the beliefs and behaviors of participants in a particular context, and allow questions to emerge from these broad inquiries rather than specifying hypotheses in advance. Because predetermined categories of events are not counted, and participants are not surveyed regarding prespecified beliefs, this method does not generate the denominator data needed to report meaningful rates or proportions. Instead, it supports an iterative process of observation and thematic development that strives to incorporate multiple perspectives, and aims to identify critical issues and hypotheses for further study.

In the medical setting, many focused ethnographies rely on the qualitative analysis of in-depth interviews.^{28,29} In this study, we supplemented interview data with direct observation of interactions between hospitalized drug-using patients and their physician teams in order both to capture qualities of their relationship that might not be easily articulated³⁰ and to corroborate participants' stated beliefs with observed behaviors.

The study was approved by the Human Subjects Review Committee of the University of Washington in Seattle. Because of the potentially sensitive data collected, a Certificate of Confidentiality was obtained from the National Institute on Drug Abuse. Written informed consent was obtained from all patients and physicians who were tape-recorded, and verbal consent obtained from indirectly involved staff.

Research Setting

The study was conducted over approximately 20 weeks between June and December 1997 on the inpatient internal medicine service of a public urban teaching hospital. At the time of the study, no addiction consultation services were available, and waiting periods for methadone maintenance programs were at least 1 to 2 months.

Participants

Eight inpatient physician teams participated in the study. Patients actively engaged in illicit injection drug or crack cocaine use were recruited during the course of thirty-one 24-hour periods. The admitting resident identified potential patients using routine clinical information available from emergency department records and staff. Patients were approached for consent after the decision to admit had been made, but before the inpatient team had performed their initial assessment.

Data Sources

Patients and their physician teams were followed throughout the patients' hospitalization. Initial interactions between patients and their physicians were observed and tape-recorded when feasible. Morning work rounds were observed each day, as were approximately half of teaching rounds. While the focus was on the patients and their primary medical teams, some interactions between patients and the nursing staff, social workers, and consultants were also observed. These data, along with informal observation and discussion of the course of care with patients, physicians, and staff were documented using ethnographic field notes. These notes included handwritten recordings of conversations, comments, sequences of events, and researcher reflections on developing themes.²⁷

Close to the time of patient discharge, semistructured tape-recorded interviews were conducted with each patient and with at least one of their physicians. Interviews began with open-ended questions about the events of the particular hospitalization (e.g., "How did things go with this patient?"). Areas that patients or physicians identified as troubling or associated with conflict were probed further. Patients and physicians were also asked to reflect on previous noteworthy experiences related to the medical care of drug users. A single researcher (JOM) collected all data after being introduced to both patients and physicians as a physician-researcher uninvolved in the patients' medical care.

Analysis

Tape recordings were transcribed when technically feasible and transcriptions reviewed for accuracy. Field notes, tape recordings, and transcripts were reviewed multiple times throughout the data collection process and coded to identify major themes. Tentative themes were explored in greater depth with subsequent subjects and then modified; this process was repeated throughout the study. Frequently encountered or emotionally charged themes were grouped and studied for patterns and connections, and data discordant with these major themes was particularly noted. Trustworthiness,³¹ the qualitative research analog of reliability and validity, was enhanced through the iterative process of reviewing emergent themes with multiple patient and physician participants.

In addition, the data were reviewed with a medical anthropologist and an addictive behaviors expert, and presented for review by colleagues in a variety of settings.

RESULTS

Participants

Twelve percent of the patients admitted to the teams under study were known to be active users of injection drugs or crack cocaine at the time of admission, and were therefore eligible for the study. Nineteen of 27 eligible patients were enrolled, with 7 eligible patients not enrolled due to the logistics of consent during busy call nights. One patient refused to participate, after suffering an iatrogenic pneumothorax.

Patients' median age was 45 (range 32 to 70); 12 were male and 7 female. Eleven were white, 7 African American and 1 Latino. Five had not completed high school, 2 had completed high school and 12 had attended some college. Six were homeless and 2 were employed. Fourteen were current daily drug injectors, 3 had stopped daily use less than 1 month prior to admission (2 in jail and 1 through inpatient detoxification), 1 had been injecting daily until given pain medications for a severe arm infection, and 1 currently smoked crack cocaine and injected heroin occasionally. The main substance of choice was heroin for 18 subjects and crack for 1, though all study patients used more than 1 substance, and 9 regularly injected a combination of heroin and cocaine. The mean duration of use was 13 years (range 1.5 to 35 years). Ten patients had been in methadone maintenance treatment at some time, and all but one had been in some form of drug treatment. Sixteen had a history of drug-related incarceration. Seventeen had previously suffered medical complications of needle use, including 16 with soft-tissue infections, 3 with endocarditis, and 2 with HIV. Hepatitis and overdose were not explicitly assessed. The most common admitting diagnoses were soft tissue (47%) or pulmonary (21%) infections.

Physician subjects included 11 junior residents ("interns"), 1 fourth-year medical student acting as a junior resident, 8 senior residents (post-graduate year 2 or 3) and 8 attending physicians. Twenty-one were male and 8 female; 24 were white, 3 Asian American, 1 African American and 1 Latino. No physician subjects refused to participate.

Major Themes

Four major themes describe the interactions between these primarily opiate-addicted patients and their physician teams. First, physicians were fearful of being deceived by patients with opiate addiction. Second, they lacked a standard approach to assessment or treatment of clinical issues commonly encountered in this setting, especially the management of pain and opiate withdrawal. Third, physicians avoided engaging patients regarding key patient complaints, and expressed discomfort and uncertainty in their approach to these patients. Fourth, patients were

sensitive to the possibility of poor medical care, often interpreting physician inconsistency as a sign of intentional mistreatment.

While these themes were manifest in a wide variety of issues, they were particularly crystallized in the context of opiate prescription. All patients in our sample were prescribed opiates for the treatment of pain or withdrawal. Opiate prescription was a common subject during the interactions between physicians and patients during work and teaching rounds and in interviews with both patients and physicians when they were asked to describe previous difficult encounters. While the prescription of opiates was not universally problematic and was only occasionally the subject of direct conflict, it was an area in which both patients and physicians expressed ambivalence and discomfort.

Fear of Deception. Physicians consistently described their apprehension about being deceived by the patients under study, and opiate prescription was a focal point for such fear. They wondered whether requests for opiate treatment might result from the patients' addictive behavior rather than from what physicians might perceive as medically indicated treatment, and feared being manipulated into inappropriate prescribing. While physicians did not express mistrust of every patient, the "legitimacy" of patient requests was an active concern, and they mentioned previous negative experiences with drug-using patients as powerful influences. As described by two medical residents:

All of us go through a little bit of a hitch every time we are requested to prescribe narcotics for our patients.... Are they trying to get more out of me than they really should have? The last thing I want to do is over-dose them or reinforce this behavior (of) trying to coax more drugs out of you.—Senior Medical Resident

When the patient is always seeking, there is a sort of a tone, always complaining and always trying to get more. It's that seeking behavior that puts you off, regardless of what's going on, it just puts you off.—Junior Medical Resident

Even when drug-using patients and their physicians were able to develop good rapport during a hospitalization, physicians commonly viewed this as atypical.

Many patients recognized physicians' fear of being deceived or manipulated, and often wondered whether this influenced their treatment. One 34-year-old man who developed an excellent relationship with his medical team described a previous hospital experience:

Maybe they thought I was coming in to get drugs or something, to get high. I didn't care what they gave. Just a local would have been OK. It's painful to cut into someone's arm like that. I would have thought they would realize that.

Physicians were not alone in expressing negative expectations of drug-using patients. Some of the most emotional comments condemning manipulative, "drug-seeking"

patients came from other drug-using patients, who strongly resented the resulting difficulty in obtaining legitimate pain management.

No Standard Approach. Assessments of patients' substance use history, current drug use patterns, and related symptoms were inconsistent. In particular, the evaluation and treatment of pain and withdrawal were extremely variable, with no common approach or clearly articulated standards. Physicians were often aware of their own inconsistency:

I don't know if it's arbitrary, if someone gives me the right feeling, or dupes me enough that they kind of talk me into it.... I give it to some people and am a lot more stingy with other people. I don't know why.—Senior Medical Resident

Everybody has an idea of how to do it, and they are all different.—Junior Medical Resident

Attending physicians rarely gave guidance regarding treatment of pain or withdrawal in spite of house staff uncertainty.

Patients' subjective statements concerning pain or incipient withdrawal were sometimes accepted. At other times, skepticism of patients' motives led to attempts to judge the appropriateness of opiate prescription on the basis of objective evidence such as vital signs.

...since there is this manipulative interaction, almost antagonistic interaction, most doctors take the tack of being cautious, and if in error under-treating, wait for vital sign abnormalities or objective findings, and in the meantime the patients are uncomfortable. We just treat them differently.—Senior Medical Resident

In searching for criteria to determine when opiates might be withheld, some physicians went beyond overt patient signs or symptoms and focused on very subtle clues.

I can tell they are playing games by their intonation, their voice, their body language. They are saying, "I will talk the way you want to get the drugs I need." It's all veiled in a whole body language to get the drug. Being ill is secondary.—Junior Medical Resident

While all patients eventually received methadone or other opiates to assuage pain or withdrawal, physicians struggled with the rationale for withdrawal treatment. Citing the long waiting lists for methadone maintenance treatment, one resident described the hospital use of methadone as "a bridge to nowhere." While some physicians saw methadone as a tool to assist patients in adhering to needed medical treatment, others suggested limiting its use to those with more severe medical conditions.

Patients who had had multiple encounters with the medical system noticed this variability most. A 32-year-old musician who had just undergone an incision and drainage of a hand abscess commented:

The last time, they took me to the operating room, put me to sleep, gave me pain meds, and I was in and out in two

days.... This crew was hard! It's like the Civil War. "He's a trooper, get out the saw...."

Patients offered various interpretations of physician variability, attributing it to lack of interest, poor clinical skills, or physician bias against drug users.

Avoidance. Physicians focused primarily on familiar acute medical problems, and avoided the more uncertain areas of assessing or intervening in the underlying addiction problem. Even the acute medical issues of pain and withdrawal were evaded by physicians during encounters with patients.

Resident: "Good morning."

Patient: "I'm in terrible pain."

Resident: "This is Dr. Attending and Dr. Intern, who will be taking care of you."

Patient: "I'm in terrible pain."

Attending: "We're going to look at your foot."

Patient: "I'm in terrible pain...."

Resident: "Did his dressing get changed?"

Patient: "Please don't hurt me."

While this dialog shows a profound avoidance of a patient's pain, most other interactions were not so extreme. Nevertheless, patients initiated discussions of pain and withdrawal far more often than physicians, and treatment plans were seldom mentioned, especially during initial interactions. The risk and benefits of methadone treatment were infrequently disclosed. Similarly, while physicians were concerned with the possibility of in-hospital illicit drug use, they discussed it with patients only in reaction to suspicious events. The possibility that such use might result from inadequate treatment of pain or withdrawal was never mentioned.

Patient Fear of Mistreatment. These opiate-addicted patients interpreted physician inconsistency and avoidance as signs of bias. Patients were fearful that they would be punished for their drug use by poor medical care. They were concerned that even delays easily attributable to hospital inefficiency actually represented intentional mistreatment. Even subtle clues to physicians' condescending or hostile attitudes became magnified for patients.

I mentioned that I would need methadone, and I heard one of them chuckle... in a negative, condescending way. You're very sensitive because you expect problems getting adequate pain management because you have a history of drug abuse.... He showed me that he was actually in the opposite corner, across the ring from me.

While nearly all patients expressed some fear of mistreatment, patients who described prior negative encounters with the medical system were most vigilant and least likely to give physicians the benefit of the

doubt. They, in turn, were perceived by physicians to be the least cooperative and truthful, and their hospitalizations were characterized by more negative interactions and frustration on the part of both patients and physicians.

DISCUSSION

This study employed a unique ethnographic approach to shed light on the nature of interactions between physicians and opiate-addicted patients in a teaching hospital. Drug-using patients and their physicians were mutually suspicious and uncertain about how to approach each other, and opiate prescription for the treatment of pain or withdrawal was a common focal point of their distrust. Physicians' approaches to these clinical issues were extremely variable. This inconsistency and the avoidance of key addiction and pain issues frequently interacted with patients' fear of mistreatment, resulting in poor communication and frustration. Prior experiences of the exceptionally difficult drug user or of the seemingly abusive and stigmatizing physician powerfully influenced subsequent interactions.

These data are consistent with previous assertions that physicians are hesitant to treat pain in patients with substance abuse problems.^{5,32-35} The management of pain is a well-documented area of poor physician performance,³⁶⁻³⁸ and when patients are opiate tolerant, the technical difficulty increases.³⁹ Yet in the hospital setting, pain treatment is generally safe, has minimal addictive potential,³⁹⁻⁴¹ and enjoys legal protections.^{5,8} Similarly, the treatment of opiate withdrawal symptoms in the hospital is permitted outside federally licensed addiction programs.^{9,42} Such treatment can minimize diagnostic confusion caused by these symptoms⁴³ and allow opiate-addicted patients access to hospital care without mandatory detoxification. Delay in treating pain or withdrawal, whether due to the fear of deception or inexperience, may lead to in-hospital illicit drug use or reduce patients' willingness to remain in the hospital.⁴³ It may also hinder the establishment of a therapeutic relationship that might more effectively address a patient's primary addiction problem.

The broad and multifaceted ethnographic approach used in this study aims to develop specific themes that are inherently exploratory, and that require confirmation and extension through a variety of other methodologies. Should these themes be supported, more general hypotheses could be broached that have implications for medical education in both pain management and addiction medicine.

This research raises fundamental questions about attitudes toward drug users in the teaching hospital. Physicians did not clearly identify patients' primary addiction as a medical disorder requiring careful evaluation and treatment. Thus, problematic behaviors tended to be interpreted in terms of patient deception or manipulation rather than as manifestations of a medical disorder.

Physicians felt obliged to guard the keys to the "narc" cabinet, distinguishing the "drug seeker" from the patient with "legitimate" medical issues. Yet this role is in stark contrast to a patient-centered approach to medical care that values the empathetic elicitation of patients' symptoms and autonomous preferences for treatment. Thus, physicians found themselves in a gray area between patient advocacy and police oversight.

The conflicting roles experienced by physicians on the medical wards are arguably not the result of clinical or regulatory demands, since pain and withdrawal symptom management is both clinically prudent and legally sanctioned. Rather, it might be hypothesized that they reflect the influence of negative societal attitudes toward opiate-addicted persons. Previous reports have documented negative physician attitudes toward patients with addictive disorders.^{4,44} The pressures to combat addiction through coercive means may spill into the practice of medicine at the expense of optimal patient care practices and the development of empathetic care providers. Thus, another possible hypothesis is that the tension of these conflicting roles threatens the development of core physician values and professional identity at a formative time in physician education. Educational efforts to improve care in this setting might therefore need to address the influence of societal attitudes toward addiction on the development of physicians' professional identity.

Yet physicians did not directly articulate the tension between these dual expectations. They expressed a vague sense of ambivalence or defensiveness but, unlike many patients, did not attribute avoidance or inconsistency to punishment or retaliation for drug addiction. These physician behaviors that appear associated with polarized interactions between physicians and drug-using patients may result in part from insufficient clinical tools to address pain and addiction management. This hypothesis is supported by a well-documented under-emphasis on both pain management and addiction issues in medical education. The additional complexity encountered when both pain and addiction complicate clinical care suggests that teaching these simultaneously might be of benefit. Recent efforts to forge ties between pain and addiction specialists⁴⁵⁻⁴⁷ are important first steps that could lead to improved training for physicians. The implementation of blended addiction and pain management education may benefit from the involvement of hospital addiction medicine and pain consultation services.

In addition to providing physicians with the tools to assess and treat pain and withdrawal, educational efforts in this arena could also promote more effective counseling approaches to drug users in the hospital setting. A proactive rather than reactive discussion of opiate prescription in the hospital could provide an opportunity to reduce miscommunication and relieve patients' fears. The development of constructive relationships might also be facilitated by motivational interviewing,⁴⁸ a nonconfrontational approach to addressing addictive behavior matched

to a patient's stage of motivation. This approach encourages the active exploration of a patient's ambivalence regarding addiction in order to both reduce resistance to behavior change and promote the development of a rapport that gives credence to directive recommendations about the importance of addiction treatment.⁴⁹

The educational deficiencies in both pain management and addiction medicine can be at least partially attributed to the historical separation of addiction treatment from medical practice. Physicians have been discouraged from using opiates to treat pain by the fear of causing addiction or incurring medical board sanctions. Future initiatives enabling physician prescription of medications to treat addiction would give physicians medical tools to feel more effective in the face of addiction and add further relevance to addiction education.

As these data were collected, certain limitations became apparent. Patients with opiate addiction, in contrast to patients with addictions to other drugs, were likely over-sampled, since potential medical treatment of withdrawal gives opiate users a strong incentive to disclose their addiction. Thus, the study findings pertain only to opiate-addicted patients. Patient interactions with nursing staff, the literal holders of "the keys to the 'narc cabinet'" were not sampled consistently because nurses' unscheduled visits are difficult to anticipate. Similarly, the attending physician perspective is under-represented, because most observations of attending physician encounters with patients were in the context of team rounds the day after admission. The focus of this study was on the central role of medical house officers, highlighting the arena of internists' formative experiences with the care of these patients.

All participants knew they were under observation, and therefore may have avoided more overt statements of bias or acts of hostility. Consequently, this data might underestimate the extent of such behavior for both physicians and patients; it is unlikely that the act of observation made things worse.

This ethnographic analysis relies on data sampled from the complex social environment of the hospital, including interactions between multiple participants in more- and less-formal medical settings (rounds, patient visits, interviews, informal discussions, etc.), rather than a more systematic sampling of a narrower range of data. Thus the observer's ability to accurately and fairly select and record events determines the scope and focus of any data that others might independently assess. While physician and patient subjects were given the opportunity to reflect on the major themes as they were being developed, they did not participate in subsequent analysis and might not have agreed with the final interpretations.

The medical care of opiate-addicted patients in a teaching hospital requires physicians to simultaneously treat acute medical problems, manage pain and withdrawal, and attend to an addiction that has often caused physical and psychosocial devastation. Physicians in this setting often lack important clinical skills and experience in

addiction medicine and pain management. Moreover, physicians and patients enter their relationship with an uncertainty and trepidation that may complicate clinical management and threaten the development of professional identity and empathy. Efforts to provide physicians with further addiction and pain management tools, and to integrate addiction interventions into medical settings may be first steps toward altering the dynamic of mutual mistrust that can come between physicians and drug-using patients.

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MAT

Medication-assisted therapy. Treatment approach that uses opioid substitution therapy (OST) with methadone, buprenorphine, or other agonists or antagonists to support antiretroviral therapy for opioid-dependent patients with HIV infection.

Methadone

Opioid agonist in liquid form which has long been used for OST. Methadone-maintenance therapy (MMT) is a widely used approach to treat heroin and other opioid dependency.

NSP

Needle and syringe programmes. A core component of harm reduction. NSPs provide sterile injection equipment, and get used equipment out of use and safely disposed. An entry point into treatment and care for many heavy users.

Opioids

Large class of agents, licit and illicit, derived from active compounds of the opium poppy, *Papaver somniferum*. Opium paste or base is the raw plant extract, generally smoked. Morphine is major active component. The diacetylated form of morphine is heroin. Opioids in common medical use include morphine, codeine, demerol, dilaudid, and oxycontin. Potent analgesics that mimic agonists (endorphins) at endogenous receptors in mammalian brain, they all have capacity to induce dependence.

Risk environment

The structural, social, political, and environmental contexts and influences that can drive or reduce risk practices and vulnerabilities.

We want this Series to be an inflection point in the history of injecting drug use and HIV infection. We want to see the latest scientific evidence trigger a more humane response to this, one of the most preventable sources of HIV disease. And we want to see inappropriately aggressive, state-sponsored hostility to drug users replaced by enlightened, scientifically driven attitudes and more equitable societal responses. We recognise that the barriers to these hopes are many and

deeply rooted across continents and cultures. But we also know that science can catalyse unprecedented social change, and unprecedented social change is what is needed for the millions of marginalised people infected with HIV who use drugs.

Richard Horton, Pam Das

The Lancet, London NW1 7BY, UK

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W 12 myths about HIV/AIDS and people who use drugs

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People who use drugs too often face stigma, discrimination, and mistreatment in HIV prevention, treatment, and care. Some societies consider such users less deserving of compassion than others with HIV who are not drug users, because users' health problems are self-inflicted or their substance use is judged as a moral or personal failing. Even among health-care providers, many preconceptions prevail about people who use drugs and are infected with HIV. What are these myths (panel)?

Drug users are non-compliant—In a meta-analysis of adherence to antiretroviral therapy from 38 studies

and nearly 15 000 patients, of whom 76% were drug users, overall adherence was similar to that reported for other populations with sexual exposure histories that were taking antiretrovirals.¹ Better outcomes with antiretrovirals were associated with being on opioid-substitution therapy, receiving psychosocial support, or both. The meta-analysis concluded that HIV-positive drug users tended to be inappropriately assumed to be less compliant and unlikely to achieve desirable treatment outcomes than non-drug-using cohorts.

Drug users do not respond as well to antiretrovirals as do non-drug-using patients—A comparison of survival rates in 3116 antiretroviral-naïve patients started on antiretrovirals (in Vancouver, Canada), of whom 915 were injecting drug users, showed similar all-cause mortality by 84 months after starting antiretrovirals.² In a multivariate time-updated Cox's regression, the hazard ratio of mortality did not significantly differ between injecting drug users and those who did not inject drugs (1.09, 95% CI 0.92–1.29). Injection drug use was not associated with decreased survival in patients who had started on antiretrovirals.

Drug users are difficult to study and have poor retention rates in cohorts, making prospective research studies with drug users difficult or impossible—The first phase 3 HIV-vaccine efficacy trial in a developing country was the AIDSVAX B/E (VaxGen) trial in 2546 injecting drug users in Bangkok, Thailand.³ Although the vaccine failed to elicit protection, the trial was successfully conducted with 2295 (90.1%) of participants retained at 36 months and an overall HIV incidence of 3.4 per 100 person-years. Such excellent retention shows the willingness of people who use drugs to enrol and stay in prospective studies.

Drug users are more concerned about getting high than using injecting equipment safely—In a study of 760 participants who used a supervised injecting facility in Vancouver, Canada, more consistent use of the facility was associated with safer injecting behaviours than was less consistent use, including less syringe re-use (odds ratio [OR] 2.16, 95% CI 1.48–3.16), use of clean water for injecting (3.15, 2.26–4.39), safer disposal of syringes (2.22, 1.54–3.20), and less injecting outdoors (2.99, 2.13–4.21).⁴ Given the choice, people who use drugs preferred safe and clean equipment.

Drug users don't have much sex; their HIV risks are largely or entirely from needle sharing—One of us (SAS) with others⁵ explored sex differences in HIV seroconversion in 1447 male and 427 female injecting drug users in Baltimore, MD, USA, over 10 years. Incident HIV infection in men was associated with young age, recent needle sharing with multiple partners, and daily use; but the incidence of HIV infection was double in men engaging in recent sex with other men compared with men who did not engage in this behaviour. For women who injected drugs, risks related to heterosexual sex were more closely associated with HIV infection than were drug-related risks.

Panel: 12 myths about HIV/AIDS and people who use drugs

- 1 Drug users are non-compliant
- 2 Drug users do not respond as well to antiretrovirals as do non-drug-using patients
- 3 Drug users are difficult to study and have poor retention rates in cohorts, making prospective research studies with drug users difficult or impossible
- 4 Drug users are more concerned about getting high than using injecting equipment safely
- 5 Drug users don't have much sex; their HIV risks are largely or entirely from needle sharing
- 6 If drug users keep using, it is almost inevitable that they will acquire HIV infection
- 7 Unlike gay men or sex workers, drug users don't have strong communities, so community interventions are unlikely to work
- 8 Rates of drug use are higher among minorities in the USA and other industrialised countries
- 9 Needle exchanges encourage drug use
- 10 Methadone (or buprenorphine) treatment just exchanges one drug for another
- 11 People who use stimulants are all heavy, out-of-control users who won't change their risky behaviours
- 12 Fear is an effective deterrent for drug use

If drug users keep using, it is almost inevitable that they will acquire HIV infection—The most recent data from the US Centers for Disease Control and Prevention (CDC) on new HIV infections in the USA among men and women who inject drugs show there has been a decline in the number of new cases in injecting drug users of both sexes from 1998 to 2007,⁶ although the prevalence of injecting drug use has been stable or modestly increasing across the USA since 2000.⁷

Unlike gay men or sex workers, drug users don't have strong communities, so community interventions are unlikely to work—The Thai Drug Users Network organised hundreds of drug users across Thailand to protest human rights violations against people who use drugs during the 2003–04 crack-down which led to thousands of drug users being executed.⁸ The Network engaged in local and regional advocacy, and successfully obtained a Global Fund grant.

Rates of drug use are higher among minorities in the USA and other industrialised countries—According to the 2006 National Survey on Drug Use and Health,⁹ African-Americans and whites have similar patterns of illicit drug use. According to the 2006 findings from the Monitoring the Future study, African-American students in the 8th, 10th, and 12th grades have substantially lower rates of use



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for most illicit drugs than do white students.⁹ A 2009 CDC report found that white injecting drug users had higher rates of needle-sharing than did minority-group users.¹⁰ Incarceration rates for offences related to substance use, however, do differ by race; with the highest rates of incarceration being among African-Americans.¹¹

Needle exchanges encourage drug use—There is no evidence to suggest that, after the introduction of a needle-exchange programme, rates of drug use or starting to inject increase.¹² A study of 600 injecting drug users in Alaska, USA, randomised users to receive access to needle exchange compared with training on buying needles and syringes from pharmacies, to test whether access to needle exchange increased the frequency of injection.¹³ There was no difference in the amount of injecting drug use between these two groups at 6 or 12 months ($p=0.0001$).

Methadone (or buprenorphine) treatment just exchanges one drug for another—A Cochrane review that included 1969 participants in six randomised trials showed that methadone was superior to non-pharmacological approaches in retaining patients in treatment, and in reducing heroin use, measured by self-report and urine or hair analysis (relative risk 0.6, 95% CI 0.56–0.78).¹⁴ Another Cochrane review showed that medium and high doses of buprenorphine were more successful than placebo alone at decreasing heroin use.¹⁵

People who use stimulants are all heavy, out-of-control users who won't change their risky behaviours—Mausbach and colleagues,^{16,17} showed reductions in sexual-risk

behaviour by HIV-negative heterosexuals and by HIV-positive men who have sex with men, despite ongoing use of methamphetamine. These behavioural interventions show that users of stimulants can reduce their risks for sexual acquisition of HIV infection, even if their drug use continues.

Fear is an effective deterrent for drug use—The US Institute of Medicine report reviewed the evidence for fear-based campaigns as deterrents for substance use and found they had no effectiveness.¹⁸

Biases and stigma against those who use drugs, are drug-dependent, or have a history of injecting are common. Such biases have no place in the practice of medicine or in the allocation of public health resources. The myths about HIV acquisition and people who use drugs are straightforwardly countered by scientific evidence, but like so many forms of prejudice, they persist despite the evidence. It is past time for these prejudices to change. Providers, decision makers, and all engaged in the global fight against HIV infection have an obligation to examine biases against people who use drugs, learn the facts beyond the myths, and let evidence drive responses.

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PARP inhibition in BRCA-mutated breast and ovarian cancers

More than 1 million women globally are diagnosed with breast or ovarian cancer every year, and 5–10% of them carry a germline mutation in *BRCA1* or *BRCA2*.^{1–3} Inside the complex of DNA repair machinery, the BRCA proteins play a crucial role via homologous recombination, while poly(ADP)-ribose polymerase (PARP) is the key component in base-excision repair of DNA. Preclinical studies showed that inhibition of PARP would lead to selective and significant killing of *BRCA*-mutated cancer cells, a phenomenon described as synthetic lethality that is not observed in cells with intact BRCA function.^{4,5}

In *The Lancet* today are two phase 2 studies of olaparib, an oral PARP inhibitor, for patients with advanced breast cancer or recurrent ovarian cancer who harbour *BRCA1* or *BRCA2* mutations. Both studies are well conducted in multiple high-quality centres around the world. The accrual rate of about 0.5 patients screened per centre per month for these relatively uncommon study populations is impressive. Using olaparib 400 mg twice daily, Andrew Tutt and colleagues⁶ reported a tumour response rate of 41% for patients with breast cancer, while William Audeh and co-workers⁷ reported a tumour response rate of 33% for patients with ovarian cancer. Additionally, both studies reported similar clinical benefit rates of 52% and median progression-free survival of about 6 months. Severe toxicities were rare in both studies, with only one treatment discontinuation due to treatment-related adverse events in each trial.

These remarkable tumour response rates have undoubtedly proven the concept that a PARP inhibitor

can suppress tumour growth in patients with *BRCA*-mutated cancers. All enrolled patients were heavily pretreated and had poor prognoses. The response rates were significantly better than the expected rate of 20% or less with cytotoxic chemotherapy.^{8,9} It seems that PARP is the right target, and olaparib has successfully hit the target in both cancers. These two studies are the first to show successful PARP inhibition in two different cancers with identical pathogenic genetic defects. The findings contribute to the evolving concept of genetic classification of cancer. Traditionally, we rely on histology and site of origin to classify and treat cancers. With emerging targeted agents aimed at specific molecular defects (eg, rituximab for CD20-positive lymphoma, trastuzumab for HER2-overexpressed breast cancer, or gefitinib for non-small-cell lung cancer with EGFR mutation), molecular classification of cancer will invariably become more informative than conventional classification for the guidance of targeted therapy, and *BRCA* mutation might be integrated into the classification of breast and ovarian cancer.

However, today's results might not reflect the complete picture. Successful targeted therapy relies on specific inhibition of a driving molecule or pathway and, upon inhibition, the typical tumour response rate is in the range of 50–70% and the disease control rate is more than 80% (table). If the synthetic lethality generated by the inhibition of PARP in *BRCA*-mutated cancer suppresses tumour growth as proposed by preclinical models, a similar magnitude of response should have

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